Health perceptions and adherence to diet

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Advances in the medical and technological field have greatly extended the life-expectancy of individuals with chronic conditions. However, such individuals may still experience difficulties in various domains such as in adjusting to their condition and in adhering to a recommended treatment regimen. Hence, one potential role of research on health perspectives is to provide information on factors which contribute to the favorable management of a chronic condition. This paper will utilize Leventhal's self-regulation model[1] in order to explain plausible cognitive factors that may have an influence on adherence to a diet regimen.

Introduction

Many persons in their mid and late adult life are confronted with one or more chronic disease.[2] These diseases may pose various challenges and threats to the individual and many times to members of his/her own social network. An example of a possible challenge faced, is the preparation of and adherence of the individual to a strict diet. As health professionals it is of major concern that various individuals do not adhere fully to their diet, even though it is a vital component of their treatment regimen. In order to understand such illness behaviours one must appreciate that persons with chronic conditions constantly weigh how necessary a prescribed diet is perceived to be, relative to any concerns they may have in following such a diet.[3] Moreover, their health perceptions regarding a treatment regimen is built up and influenced by various sources such as personal experiences, past experiences with the disease, information obtained from contact with others (e.g: health professionals, friends, relatives), as well as the media, cultural and social influences about health and illness and the internet.[4,5]

Various health models have been proposed to explain non-adherence to treatment. In this article, we will be utilizing, the self-regulatory model of illness behaviour,[1,6] as a framework to comprehend non-adherence to treatment. This model will be adopted due to its special relevance in explaining and predicting patient adjustment and adherence to treatment regimens[7] and will be described in the following section.

The Self-Regulatory model

This model posits that individuals are active agents who form illness representations regarding their condition. These perceptions and beliefs are dynamic and changing as the individual tries to understand and regulate his/her condition. Moreover, these health representations play an important role in influencing and regulating the coping strategies adopted, and via coping, various outcome measures such as adherence to treatment and emotional reactions.[8] Research emanating from a number of different medical conditions implicates that these health perceptions consist of seven cognitive dimensions. The first dimension, identity is concerned with the illness label (e.g: celiac) and its concrete symptoms (e.g: feelings of bloatedness). The time-line dimension is divided into an acute/chronic subscale and also a cyclical subscale which incorporates whether the person perceived his/her condition as cyclical in nature. The consequences dimension comprises the individual's perceptions regarding the short and long term impact of the disease on his/her life as well as the individual's belief on illness severity. The causal dimension is based on the individual's perceptions on the potential causes of the illness. Personal control refers to beliefs about one's own ability to control symptoms whilst treatment control is an indication of the patient's belief on treatment effectiveness in controlling their illness. As a measure of the emotional impact of the condition, an emotional representation dimension was included. The illness coherence dimension measures the individual's perceived overall understanding of their illness.

These various illness dimensions, which have been put forward in the self-regulation model will be exemplified in this paper using the coeliac condition as an example. This chronic condition is one which requires

strict adherence of the individual to a gluten-free diet. However, it is imperative to add that the points raised in this article could also be applied to any other chronic condition which requires adherence to a prescribed diet.

Types of non-adherence

Non-adherence to treatment can be categorized as shown:

i) unintentional: this occurs when the individual wishes to follow the diet but is prevented from doing so due to some *unintentional* factor, such as poor comprehension of diet requirements;

ii) intentional: when the individual takes a voluntary decision not to follow their prescribed diet to various degrees.

Aim

The aim of this paper is to illustrate how the self regulation model provides a framework to understand possible causes of non-adherence to diet in coeliac patients.

Method
Participants

In order to investigate these illness dimensions, a total sample of 40 Maltese adolescent and adult coeliac individuals were interviewed. These participants formed part of a larger sample (N=197) of patients having a range of chronic genetic conditions and who participated in a 3 year longitudinal study by the first author for her doctoral requirements. Eligibility criteria included that the diagnosis of the coeliac condition was confirmed by a small intestinal biopsy, that the individuals were above 12 years old (adolescents) and that they had been diagnosed with their condition for at least 6 months.

Procedure and measures

The following procedure was adopted to recruit coeliac individuals. Both health professionals and the coeliac support groups were contacted. The participant was first approached by the health professional or a key member of the coeliac support group and the nature and purpose of the investigation was explained to the individual. In all cases, the rights of the person/s to decline participation was/were respected. Selection of individuals from the list of members of the coeliac support association was computed by giving each member a number (1 to N, where N is the total number of members in the association) and using a computer program to randomly select the number of participants required. Participants demonstrating a willingness to participate in the study were then approached by the first author. It was decided to contact them initially by telephone rather than by written contact as any queries could be immediately clarified.

The coeliac individuals were administered a questionnaire designed by the first author to examine demographics, causal attributions for disease and lifestyle changes. The construct validity (determined by factor analysis) and reliability (determined from Cronbach alpha values, test-retest reliabilities and inter-item correlations) of this instrument have been established.[9] The items in the questionnaire were read out by the first author and the patients provided written responses. All the interviewing was completed in the location requested by the patient, to ensure that the participant would feel at ease. It was carried out by the first author in Maltese or English depending on the request of the participants. Moreover, for adolescents under the age of 16, parental consent to participate in the study was first obtained and the interview was held in the presence of a family member. The purpose behind the study was explained to the subjects and they were instructed that their responses would remain confidential. The whole procedure lasted on average about 60 minutes.

For the purpose of this paper, quotes dealing with treatment adherence were obtained from patient responses to the question on the impact of their illness to their lifestyle. This selection procedure was done however, keeping the framework of the self-regulation model in mind.

Data analysis

The written responses of patients regarding the impact of the coeliac condition, (if any),on their life-style was read by the first author and analyzed for meaningful segments. These segments (key words, phrases and explanations) were highlighted and then allocated into themes.

Two coding strategies were conducted. First, these data were examined for general life style themes. This was conducted to identify the spheres of people's lives that were affected by their illness. As this was a more inductive coding strategy a second psychologist was provided with the same scripts and working independently was asked to provide a list of possible themes under which he perceived patient responses to fall. This procedure was used to ascertain validity of this coding scheme. Inter-rater agreement was calculated between the codings provided by the two raters. The second coding strategy, was based directly on the definitions of illness representation from the self-regulation model (see introduction). This analysis was conducted solely by the first author to identify quotes that represent the categories of illness representations as described in the self-regulation model.

Results and discussion

Of the participants in this study, 75% were female. The mean age of the participants was 42.15 years (SD=15.45, range=12-78) and their mean illness duration was 6.15 years (SD= 4.57, range=1-37).

Life style thematic categories

There was a 100% inter-rater agreement regarding the following life-style thematic categories: *social* (e.g: eating out at the same restaurant), emotional (e.g: feeling different from their peer group; feeling upset that adherance to diet had not prevented the development of further complications); management of coeliac condition (e.g: eating gluten free food and following a more 'natural' diet); physical (e.g: feeling healthier) and spiritual (e.g: stopped attending mass). Then individual patient quotes on adherence, falling under these life-style themes, were then selected on the basis that they related to the illness representations that are listed below.

Illness perceptions

The following examples illustrate the major dimensions of illness representations and how patient's perceptions on the impact of their illness may influence their adherence. Example quotes for the various illness representation dimension are provided.

i) *Illness coherence:* is a term indicative of one's perceived understanding of a chronic condition. Various studies such as that by Ljungman and Myrdal,[10] have demonstrated that a better knowledge of the coeliac condition is related to an increased adherence to a gluten-free diet. Thus, an incomplete picture of the coeliac condition and required dietary treatment may lead to less accurate beliefs about one's prognosis. This may ultimately have an impact on strict adherence to diet.

ii) *Timeline:* represents the perceived duration of an illness. The coeliac condition is a chronic condition for life. Thus, if an individual perceives it to be an acute (short term) condition or one cyclical in nature (e.g., seasonal), the individual him/herself may be tempted to doubt the necessity of following a strict diet for life. Such a case was documented in a study by Meyer, Leventhal and Gutman,[11] on a sample of people with chronic hypertension. It was observed that those individuals who considered their chronic condition as acute in nature tend to adhere less to the treatment regimen. The following example illustrates this point:
"I keep a list attached to the fridge with items that I am expected to avoid, but I still cheat frequently especially by eating 'normal' bread. I then begin to itch very badly but this can be helped by taking these pills which stop me from itching. I get very upset but my sister-in-law told me her friend's son was coeliac as a child but then grew out of it. I am hoping that this will happen to me too." (Female, 39 years; diagnosed 5 years ago)

iii) *Treatment control:* represents the perception that following one's treatment is beneficial. One manner to evaluate the effectiveness of a treatment is based on whether there has been an amelioration of symptoms experienced or not. Many coeliacs during the interview cited a feeling of being 'rejuvenated', 'now following a natural diet" or 'feeling healthier', after being placed on a gluten-free diet Such individuals may perceive adherence as a necessary measure that has provided them with a new lease of life. However, in other cases the individual may believe that the diet is ineffective. This may arise for example, when another chronic condition appears such as diabetes or psoriasis (in addition to the coeliac condition) or when the level of antigliadins in the blood is higher than the required norm- even though the person is allegedly following the diet. The following quote exemplifies these points:
"I have always followed my diet. At home, they accuse me of being too obsessed, as I am preoccupied with avoiding contamination of my utensils and food. Then when I go for my check-up, the level of antigliadins is found to be high. So I ask myself how could it be? I think that there is more to it than the   doctors tell us, they do not know everything yet about our disease" (Female: 52 years; diagnosed 3 years ago). In the quote cited above, the participant perceived that adhering to the diet was not effective in preventing the expression of symptoms normally associated with non-adherence. She felt confused and felt that there was some vital piece missing from the jigsaw puzzle, which represented the established present day knowledge on the coeliac condition. By adhering to the treatment, this participant was not receiving the desired outcome (acceptable blood antigliadin levels) that she expected considering her intense efforts to adhere to the diet.

iv) *Personal control:* represents a belief in one's **personal** ability to control a chronic condition. In fact, one may find individuals who emphatically stress the importance of a gluten-free diet and yet they do not perceive themselves as capable of exerting the control needed to follow it. The following quote illustrates this point:
"When I am cooking pasta for the rest of my family, I taste some of their pasta and then I spit it out. Like that at least I can enjoy the taste and then I spit it out so that I will be causing the least possible harm to my body. I do it every time. " (Female, 55 years; diagnosed 1 year ago). In such cases as shown in the previous citation, the individual is aware that she is causing harm to herself however the problem lies in her perceived inability to exert the necessary control to follow a strict gluten-free diet.

v) *Consequences and emotional representations:* this term encompasses the perceived impact (psychological, social, physical and economic) of the coeliac condition on the individual. Some persons view their condition as having a positive impact on their life. For example they will cite reasons such as 'feeling healthier'. Conversely, other individuals may quote not following a strict gluten-free diet due to for example, its impact on their social/emotional life. The quotations cited below amplify this point:
"I go out with friends and I am always making up excuses, as I do get people asking me to take a bit of this or that. Even when I tell them no, they still do not get the point. I do not feel that I should tell them that I am coeliac, as it is a personal matter. Once in a while I get tired resisting and I then I just give in"(Female, 18 years; diagnosed 5 years ago). As shown in the above example, the individual has the required knowledge of her condition but opposing the constant good intentions of her colleagues (as they do not know that she is coeliac) is proving distressful.

The following quote gives another example of the consequences (spiritual impact) of following a diet regimen. One must appreciate that till some time ago, gluten-free hosts for Holy Communion, were not yet available on the island and coeliac individuals would receive wine instead. This normally involved ensuring that the priest was aware of their condition, as well as having to be one of the first or last persons out in the church aisle in order to receive the wine in a special container or a spoon. The following quote illustrates the experience of one lady:
"When I attended church, I used to go up before everyone else to receive the wine instead of the host. One day a

group of youngsters began laughing and calling me a drunkard. My family got really upset especially my husband. Now I occasionally take the 'normal' host as it is embarrassing to stick out in a crowd and I dislike having people speaking about me."(Female, 55 years; diagnosed 18 years ago)

Another non-compliant group may be made up of those individuals who occasionally eat food with gluten and yet experience no discomforting symptoms. These persons try to make sense of these particular episodes and will often describe themselves as 'being a special type of coeliac' or 'one who is outgrowing this condition'. These persons perceive a discrepancy in what the health professionals emphasize i.e: the need to adhere to the diet and their own experiences i.e: having no symptoms normally associated with the condition. Moreover individuals often use the presence of symptoms as an indicator of illness and to determine whether a treatment is effective or not.

<table>
<tr><td>Practice points</td></tr>
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1. One must appreciate that patients are active participants in a health care process and that the former will formulate their own beliefs about their illness.
2. The health perceptions of each individual are unique and are built up from a variety of sources. Any problems arising from managing a chronic condition will be confronted on the basis of these health representations.
3. Persons with chronic disease may hold beliefs regarding their treatment which may be in conflict with that of the health professional. These perceptions and concerns must be elicited in order to enhance a therapeutic process.
4. Health professionals when introducing interventions should be sensitive and responsive to the needs and beliefs of the individual with a chronic condition.
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Conclusion

The reasons for non-adherence to a dietary regimen are diverse. In this article we examined non-adherence from a socio-cognitive perspective. We used a qualitative approach to illustrate not only the illness representation model but to illustrate that patients do use such representation when they describe and think about their illness. Additionally, one should appreciate that there are other possible reasons for non-adherence such as economic, cultural influences as well as difficulties in communication between the health professional and patient.[12]

Hence, it is vital for health professionals to appreciate that persons with chronic conditions are active agents in their treatment process and thus, are constantly striving to make sense of an illness experience. Thus, attention should be paid to perceived causes of non-adherence and these issues should be discussed with the patient. Since the clinician and patient may often have different illness representations, discussions between the professional-patient dyad may lead to a greater appreciation and understanding of each others perspective. With the establishment of such a dialogue various confusions and mis-interpretations may be minimized[13] and the health encounter between the patient and health professional may prove to be more satisfying. A number of techniques and procedures for intervention are suggested by Ferguson *et al.*[13]

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