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Adherence, behaviour change and visualisation:

A qualitative study of the experience of taking obesity medication

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Running head: adherence, behaviour change and obesity treatment

Abstract

Objective: To examine patients' experiences of taking orlistat and as a means to explore adherence and behaviour change. **Method:** Qualitative interviews with twelve participants who had taken orlistat in the past two years. **Results:** Their experiences were described in terms of beliefs about the causes of their obesity, their motivations for taking orlistat and the highly visual side effects. These themes have implications for understanding adherence and behaviour change. For some, the side effects led to non adherence and no behaviour change. These individuals seemed to be motivated by the routine effects of being overweight such as lowered self esteem. In contrast, those who were motivated by a life crisis seemed to tolerate the side effects of the drug leading to adherence. In turn, these highly visual side effects enabled them to make an explicit link between food consumed and weight creating a shift in their beliefs about the causes of obesity making behaviour change more likely. **Conclusion:** Orlistat use illustrates how treatment and illness beliefs interact to create both adherence and behaviour change particularly in the context of a life crisis and when symptoms can be visualised.

Key words: adherence, behaviour change, obesity, orlistat, visualisation.

Introduction

Most obese patients are managed through interventions involving a range of cognitive and behavioural techniques designed to facilitate changes in diet and exercise. Although some individuals lose weight with this approach an analysis of the effectiveness of behaviourally based treatments suggests that at 3 and 5 year follow ups most show weight regain back to baseline weight (1,2,3). In real terms between 90% and 95% of those who lose weight regain it within several years (3,4). In light of the general failure of behavioural interventions some clinicians have turned to more medical solutions including surgery and drugs. The surgical management of obesity has been endorsed by expert committees in the US (4) and the UK (6) but is only recommended for those with a BMI over 40kg/m^2 (or >35 with complications of obesity) as long as they made aware of the possible side effects. Surgery is therefore only available for the minority of obese patients. In contrast, drugs are available to a wider range of patients. Orlistat is one type of drug which acts on the gastrointestinal system and works by reducing fat absorption. Current recommendations suggest that it is used for patients who have a history of failed weight loss attempts using behavioural methods and who can demonstrate some degree of weight loss in the month before treatment (7). Orlistat, however, has unpleasant side effects including liquid stools, an urgency to go to the toilet and anal leakage which are particularly apparent following a high fat meal as the drug causes the fat consumed to be removed from the body. Therefore although orlistat is designed to work as a medical intervention it probably also works by deterring unhealthy eating – an ‘antabuse effect’ (8).

Some research has addressed the effectiveness of these medical approaches to obesity treatment using quantitative designs and randomised control trials. The findings indicate that surgery can be effective for both weight loss and maintenance and brings with it a reduction in the risk factors for cardiovascular disease (9,10) and that orlistat can also result in substantial weight loss (11-14). In addition, research has used a qualitative method to explore patients' experiences of surgery as a means to examine the mechanisms behind its success (15-17). Recent results from these studies indicated that surgery not only has non specific effects created by the weight loss such as improved quality of life, confidence and self esteem but also specific effects caused by the actual operation. In particular, by enforcing a reduction in the amount of food that can be eaten, surgery seems to generate changes in the individuals' relationship to food and may help to re establish a perception of control over their eating behaviour (16,17). To date, however, no research has assessed the patients' experience of taking orlistat in their attempt to lose weight. In light of this the present study used a qualitative design to explore the patients' experience of taking orlistat as a means to promote an understanding of how and why this drug may be effective.

Orlistat, however, also raises some interesting psychological questions. First, given its unpleasant side effects and that it is only effective if patients persist in taking it, the experience of taking orlistat is a useful window through which to explore the issue of adherence. Research shows that many patients do not adhere to their medication and can either show non adherence or a form of partial adherence whereby the drug is used in a way that fits in with the patients' life (18-22). For example, research on adherence to asthma medications showed that 73.2% of patients engaged in some form of partial adherence at some time (22). The degree of adherence has been

associated with a range of factors including symptom perception and patients' beliefs about their illness and treatment (22-27). In line with this the present study aimed to examine what factors determine whether or not an individual choses to adhere to their prescribed medication. Second, the side effects of orlistat can be avoided if an individual changes their eating behaviour and avoids high fat foods. Orlistat is therefore also a useful tool to examine the process of successful and unsuccessful behaviour change. Behaviour change has been studied extensively in terms of the psychological factors that predict behaviour, changes in behaviour and the development of interventions to promote change (eg. 28-31). The present study aimed to explore changes in dietary behaviour in the context of medication taking.

Method

Design

The study used a qualitative design with indepth interviews.

Sample

Interviews were carried out with twelve participants recruited from two general practices in south London (n=7) and through an organisation providing support for those on orlistat (n=5). All participants had been prescribed orlistat in the past year, 7 were women and 5 were male, most (n=10) described themselves as white whilst 1 was Black and 1 was Asian. Nine were currently taking orlistat. Of the 12 interviewees 7 had lost large amounts of weight and 5 had either regained any weight lost (n=2), not lost weight in the first place (n=2) or had been on orlistat for too short a time to judge (n=1). The participants details are shown in table 1. All are given a pseudonym.

-Insert table 1 about here -

Procedure

The interviews lasted between 30 mins and one hour and 11 of the interviews were audio taped and transcribed. For one interview detailed notes were taken due to a failure with the recording equipment. Seven interviews took place face to face either at the interviewee's home or at the general practice and 5 took place over the telephone.

Interview schedule

The study used indepth semi structured interviews with open ended questions. The interview schedule involved questions such as ' Can you tell me about your history and how you gained weight?', 'How did you find out about orlistat?', 'What is it like to take orlistat?', 'Has orlistat worked for you?'. Prompts were used to encourage participants to provide more details and to speak freely. Notes were also completed at the end of each interview concerning the style of the interview.

Data analysis

The interviews were analysed using Interpretative Phenomenological Analysis (IPA, 32,33). The transcripts were read and re-read by JO and SS to ensure familiarity with the data. For each interview a coding sheet was constructed. This sheet contained all possible themes and sub-themes for each interview. References to transcripts were recorded under each theme. From the individual summary sheets an overall list of themes was constructed. With continuous reference to the transcripts, connections across the list of themes were made. A table of themes with their various sub-themes was consequently constructed. All the verbatim transcripts were re-read to ensure that

the themes were representative of the original material. Instances of each theme in the transcripts were recorded. Throughout the write-up process, themes and sub-themes were adjusted. IPA was chosen as it emphasises 'sense making' (33) and enables an analysis of the individual's own experience and the ways in which they derive meaning from this experience whilst acknowledging the role of the researchers' own perspective. In addition, the data were minimally quantified to clarify the relationships between the different themes.

Results and discussion

The participants described their experiences of taking orlistat in terms of three broad areas: beliefs about the causes of obesity; motivations for weight loss; side effects of orlistat. These experiences will be described individually and then their implications for understanding adherence to medication and behaviour change will be explored. 'Types' of patients who do and do not benefit from taking orlistat are described elsewhere (33). The participants' codes for adherence (Yes / partial), whether their motivations for weight loss related to a significant life event (Yes / no), whether they described the side effects of the medication in a highly visual way (Yes / no) and how they conceptualised the causes of their problem (biological / behavioural) can be seen in table 1.

i)The causes of their obesity

Many of the participants described obesity as being caused by factors beyond their control. Some emphasised the genetic basis to their weight problem and how being overweight 'ran in the family'. Others looked to conditions such as diabetes, steroid use or polycystic ovaries to explain their condition. For example, Frances described how:

‘I’m not a big eater, sometimes I don’t even want to eat but I just eat coz I have to eat coz I’m diabetic’ (Frances).

Similarly Agnes, held her medication responsible for her weight:

‘My children said ‘Mummy that steroid was the one that is blowing you’… its blown me out, I can not touch my back, I cannot wash my bum’ (Agnes).

In contrast some described how their weight was due to their behaviour. For example, David who had lost weight on orlistat described how his weight gain was due to:
‘drinking too much…. eating for comfort… lived in a house where there was always much too much to eat… finishing off children’s food’ (David).

Others described how they ate too much, ate the wrong foods, ate because they were depressed and simply didn’t do any exercise. For example Matthew stated how:

‘I ate too much. I ate too much. I ate all the wrong foods. I did a static job….. And the bigger I got the more I ate. And that’s about it really. I used to eat a colossal amount…..it was bacon, eggs, sausages, chips… I used to eat loads and loads of meat. Beef, pork. I could eat two French sticks in one sitting’ (Matthew).

Beliefs about the causes of obesity therefore varied from those outside the individual’s responsibility to more controllable factors. Previous research has

explored patients' beliefs about the causes of obesity and suggests that whilst many patients prefer a more medical model (35) successful weight loss and maintenance is associated with a more psychological perspective (36). This was supported by the present study as all those who had not lost weight or regained any weight they had lost on orlistat focused on causes which were beyond their control involving genetics or illness (n=5). In contrast all of those who described the causes of their weight problem as behavioural (n=7) were those who had shown weight loss and felt that orlistat had been helpful. A belief that a weight problem is caused by behaviour and is therefore modifiable and within the individual's control seems to be more associated with successful weight loss than a sense that it is an inevitable consequence of factors beyond personal control.

ii) Motivations for weight loss

As part of their own personal histories participants described a range of attempts at weight loss and how they had tried 'diets upon diets, hospital diets, doctor diets, nurse diets, everything' (Pat). Motivations for eventually taking orlistat to promote their weight loss were varied and ranged from aspects of their self esteem and feelings of confidence to more dramatic moments of crisis.

For example, Kate stated that:

'Weight to me affects me in life because I don't feel confident at all with anything because I'm overweight…. I just don't think that people who are overweight are attractive at all…. A fat person is horrible to look at' (Kate)

Similarly, Pat described how it would be nice to be able to wear clothes from normal shops:

'Just buying clothes off the rack instead of going into certain shops, being looked at and them saying you can't come in here because you're too big…they say 'sorry love, we don't buy tents for clothes' (Pat)

In contrast to these more routine motivations relating to the day to day experience of being overweight others described extreme moments of crisis when their weight suddenly presented a real threat to their lives. For example, David was rushed into hospital with a suspected heart attack and told 'lose weight or you will die'; Tanvir woke up in hospital with collapsed lungs caused by sleep apnoea resulting from the excess pressure on his windpipe, developed double pneumonia and then went into a coma, Matthew decided to start orlistat after his fourth heart attack at the age of 37 and Marion described how 'I work in a mental hospital and she [GP] wanted to put me in it because I was feeling suicidal'.

Peter described how his life event made him decide he had to try an alternative way to lose weight:

'I got a bad chest infection and I felt so ill so I went to my GP… he sent me to Guys Hospital…. They said my blood oxygen was so low, I wasn't breathing very well anyway. I had blocked sleep apnoea… I stopped breathing for 20 seconds at a time… after that I had an irregular heart beat…. It's a defect in your heart….. I left it a bit late in life to enjoy it but I had to do something…. Or I probably would not make 52' (Peter).

In a similar vein Matthew described how after his fourth heart attack:
'It got to the stage that I knew I was going to die and that was the turning point. I knew I was going to die unless I did something about it. And then I just got into gear and it turned me right around' (Matthew).

Some participants (n=5) described their motivations for using orlistat in terms of feelings of lowered self esteem, stigma and a desire to be more attractive which have been frequently reported in the literature by both obese and overweight individuals as reasons for attempting a range of weight loss practices (37). Further, such general motivations have also been described by patients who have decided to undergo obesity surgery (16). In contrast, many (n=7) offered more dramatic incidents which find reflection in the specific symptoms also described by some surgical patients (16). These life crises were described as putting life itself into question and by raising patients' sense of mortality seemed to increase their awareness of the threat of their obesity to their health. These different motivational sets were related to outcome and those who gave more dramatic examples of why they started orlistat were the ones who were successful at weight loss (all of the 7).

iii) Side effects of taking orlistat

The patient information leaflet for orlistat describes some of the possible side effects including liquid stools and anal leakage. For the large majority of participants these side effects played a central role in their experience of taking the drug and were described in great detail. In particular, the process of visualising fat and discharge was central to their experiences. For example, Linda described what happened when she first started talking the drug:

‘I had a kebab after I first started taking them and I spent the rest of the night on the loo with my head on a pillow on the cistern behind because I daren’t go out… have something you shouldn’t have, oh boy! Its like going into labour!’ She also described the longer terms effects ‘I was leaking you know. I started putting a panty liner in because it was like ‘Oh my God’’ (Linda).

Similarly, David described how:
‘I had near misses… I don’t break wind unless I’m sitting on the loo. It’s a fear thing – I have had situations where I’ve had to discard a pair of boxer shorts’ (David).

Further, the side effects were described as ‘my own personal oil slick… very messy’ (Tanvir), ‘oily accidents’ (Frances), ‘I was on the loo nearly all bleeding day’ (Matthew).

In contrast, one participant seemed ambivalent about the meaning of any effects: ‘None at all. I had to keep going to the toilet every so often and that was it. I was fine no problems really’ (Pat).

The side effects were therefore a central component of the majority of the interviewees’ experiences (n=10). This seemed to be made particularly intense by their ability to visualise fat which was described as ‘messy’, disgusting’ and ‘horrible’ and by the fear associated with feeling ‘unsafe’, ‘near misses’ and having ‘accidents’. Previous research indicates that concerns about taking a drug can influence patients’ beliefs about the drug and their adherence (22,27). The present study illustrates that

the consequences of any side effects may be particularly heightened when the consequences are visual.

The participants therefore described their experiences of taking orlistat in terms of their beliefs about the causes of their obesity, their motivations for taking orlistat and their experiences of the side effects. These broad themes have implications for understanding adherence to medication, behaviour change and subsequent weight loss.

Implications for adherence to medication and behaviour change

Orlistat removes fat from the body producing unpleasant side effects. This produces three choices. The drug can be stopped or taken only when low fat food has been consumed resulting in non adherence or partial adherence. Alternatively the individual can adhere to their medication and tolerate the side effects or the individual can change their diet and consume food low in fat. As Tanvir said 'Either stop taking the tablets or stop eating the greasy stuff'. Taking orlistat therefore raises issues of both adherence and behaviour change.

In terms of adherence, some of those interviewed described how they used the drug to fit in with their life style (n=4). This meant not taking it when they were going to eat high fat foods, coming off the drug entirely or coming off it for long periods of time. For all interviewees the reason for this partial adherence was their experiences of the side effects which were so unpleasant. For example, Frances described how:

‘I take it all the time… I take three a day… but because of some of the side effects if I’ve got things to do outside on any particular day I don’t take it… so I don’t take it when I go out, or if I go away on holiday. No not at all’ (Frances).

This form of partial adherence has been frequently shown for other forms of medication for a range of chronic medical conditions including asthma and diabetes (17, 20, 22, 37). In the present study adherence was linked with health outcomes with these participants tending to show lower levels of weight loss or even weight regain (3 out of the 5 who didn’t lose weight). In contrast, others (n=8) described how they took the drug ‘religiously’, how they ‘treated it with the respect it was due’ (David), ‘took it three time a day… even took it if I didn’t eat anything’ (Matthew) and were ‘very very strict with myself’ (Marion). These tended to be the participants who had lost large amounts of weight (6 out of the 7 who showed weight loss).

These adherers (n=8) and partial adherers (n=4) seem to differ in three fundamental ways. First, those who did not adhere and used the drug in a more casual way were motivated to use orlistat as their treatment approach by factors such as self confidence, attractiveness and self esteem – the day to day components of being overweight (3 out of 4). In contrast, those who adhered to the drug tended to report more dramatic episodes of crisis such as illness and a sense of their own mortality which seemed to provide them with the momentum to endure the side effects in the first instance (6 showed life events out of 8). Previous research indicates that adherence is related to beliefs about both treatment and the illness, particularly beliefs about consequences (22). The present study suggests that adherence may be

particularly more likely when life crises make such beliefs about the consequence of illness particularly salient and when mortality itself is challenged.

Second, these two groups differed in terms of their degree of behaviour change which was reflected in actual weight loss. Those who did not persist with their medication or showed partial adherence did not substantially change their diet and carried on eating as they had done before (3 out of 4 did not lose weight). They had high fat meals at times when they chose not to take their medication or stopped their medication entirely to enable them to eat as they wished. In contrast, those who adhered to their medication could do so because they avoided the side effects by changing their diet (6 out of 8 lost weight). They described how they:

'cut out carbohydrate, eat fruit and vegetables, have a high protein diet… eat three meals a day religiously' (David) and:

'when I'm hungry now instead of having a packet of crisps or a kit kat and a cup of tea I'd rather have a tuna sandwich…. At night… instead of getting a chocolate or a packet of crisps, I'd have a couple of pieces of fruit…. All the [orlistat] does is just changes your eating habits' (Tanvir).

Adherence was therefore maintained by behaviour change. Research exploring behaviour change often conceptualises it as the end of a linear process from cognitions through to behaviour (31). Accordingly, behaviour changes only when there has been a substantial cognitive shift. The results from this study suggest a more complex relationship between initial adherence, side effects, behaviour change and subsequent adherence with these factors interacting in a self regulatory and dynamic way.

Finally, these two groups also differed in terms of their beliefs about the causes of obesity. Those who neither adhered nor changed their behaviour tended to offer a more medical model of causality focusing on genetics or illness. In contrast, those who changed their behaviour endorsed a much more behavioural model of obesity attributing it to their diet and exercise (8 out of 8). It may be that such beliefs pre date the onset of orlistat use with people who hold a more behavioural model being more likely to adhere to their drug regimen. This would support previous research exploring weight in obese people not taking medication (36). However, the interviews suggest that the side effects actually produced a shift in their model of causality. In particular, for some, the unpleasant side effects helped the interviewees to visualise the fat in their bodies and make the link between fat being ingested and fat either being stored or excreted. The drug for these people was therefore seen as an education that helped them to rethink why they were overweight and what they could do about it and changed their model of obesity from a medical one to one with an emphasis on behaviour. For example David described how the early side effects: 'taught me very soon. That made me think that I can't eat the bad things' (David).

Similarly Matthew described how:
'[orlistat] breaks down the fat and once you see that coming out of your body, you realise gosh what you are putting in it…..It educated me on what to eat.….' (Matthew).

and Linda described how ' I don't eat the wrong things because I know what's going to happen… it'll be another night on the toilet' (Linda).

Previous research has argued that treatment beliefs and illness beliefs exist in a dynamic relationship and that the degree of 'goodness of fit' between these two sets of beliefs may relate to health outcomes (22). The results from this study support this perspective but suggest that this dynamic is particularly apparent when the side effects of a drug can be visualised in a way that produces a shift in beliefs about the cause of the problem. Further, the results indicate that such visualisation may help to improve the goodness of fit by bringing illness beliefs and treatments beliefs more in line with each other.

The exception to this pattern was Marie who adhered to her medication but neither changed her eating behaviour nor offered a more behavioural model of the causes of her weight problem. She described the drug as:

'bringing out all the fat that I couldn't bring out' and how 'when you take them all the fat comes out' (Marie). She hadn't changed her behaviour as she believed that 'in all foods there's fat…. I've been eating this fat in most of the foods, that'll take it away, and whatever I have in that'll help it come out' (Marie).

For Marie, the drug was seen as a form of purging that legitimised a high fat diet and although she could frequently see the oily products of her food intake this visual process did not seem to enable her to make the link between eating behaviour, fat and body weight. For her, the pleasures of eating high fat food may have outweighed the unpleasantness of the side effects. Or perhaps, her understanding of nutrition and diet was such that she felt the fat content of her diet was beyond her control.

Conclusion

Orlistat offers a medical solution to obesity which has been shown to promote weight loss (eg. 11). The present study aimed to explore participants' experiences of taking orlistat. However, there are some limitations with the design of the study that need to be addressed. First the study involved a small number of participants and a qualitative design. Such a methodology enables an in depth analysis of each participants' experience and focuses on their own perspective rather than that derived from a previously developed theoretical approach. However, give the sample size and the sampling method used generalisations and broader conclusions remain tentative. Second, although links between themes emerge from the data future quantitative research is needed to test these links, particularly using a prospective design if the direction of causality is to be better understood. However, the results do provide some insights into how patients experience orlistat and the implications for adherence and behaviour change.

In terms of the patients' experiences, the results showed a central role for beliefs about the causes of obesity, motivations for weight loss and highly visual images of the side effects of the drug. Further, the interviews illustrated how these three components act on and are acted on by a dynamic relationship between adherence and behaviour change. For some, the negative experience of the medication led to non adherence with no subsequent behaviour change. These individuals seemed to be those motivated by the day to day effects of being overweight such as lowered self esteem and feelings of unattractiveness. In contrast, those that were motivated by a life crisis seemed more able to tolerate the initial side effects of the drug leading to

adherence in the first instance. In turn these highly visual side effects produced a shift in their belief about the causes of obesity enabling them to make an explicit link between food consumed and body weight which subsequently made behaviour change more likely. Such adherence and behaviour change was ultimately linked with weight loss.

Leventhal et al (24-26) argued that adherence to medication can be understood in terms of the self regulatory model with its focus on illness and emotional representations and symptom perception. This model was expanded by Horne and Weinman (22) to include a role for treatment beliefs with an emphasis on beliefs about how necessary the treatment is and any concerns held about side effects. From this perspective adherence can be conceptualised as the result of an interaction between how someone makes sense of both their illness and their medication. The present study supports this perspective and suggests that taking orlistat and subsequent weight loss were the consequence of seeing the side effects of the drug and believing that obesity is a result of one's own behaviour.

The results from this study however, suggest that this is not the whole story. First, in the case of orlistat, this link between treatment beliefs and illness beliefs can only occur if the individual initially adheres to the drug. For the present study this initial adherence seemed to relate to motivations for weight loss generated by the existence of a life crisis. Such crises have been described by the coping literature as destabilising the individual's equilibrium resulting in a desire to re establish the status quo (39,40). The present study suggests that crises may also offer a powerful momentum at the beginning of the medication process. Further, in line with Horne

and Weinman (22) by emphasising the potential serious consequences of obesity, such a crisis may highlight the 'necessity' part of participants' treatment beliefs. Second, this link between treatment beliefs and illness beliefs seems to be particularly apparent when the side effects are highly potent and enable the individual to visualise how the drug is working. Leventhal et al (25) argued for a central role for symptom perception with a focus on illness related symptoms. The present study also suggests a role for treatment symptoms, particularly those which are highly visual. Third, by making the link between diet and weight explicit this visualisation led to a shift in beliefs about the cause of the problem which in turn enabled changes in behaviour. Finally, by bringing about changes in behaviour, the side effects were minimised making continued adherence less aversive.

Research indicates that orlistat can help weight loss. The present study shows that its effectiveness is due to subsequent changes in behaviour. Future research is needed to test some of these findings. In particular, quantitative research using a prospective design could incorporate many of the themes identified in the present study as a means to predict weight loss following orlistat and to identify who might best benefit from this approach to weight management. Further the study illustrates that treatment and illness beliefs interact to create both adherence and behaviour change and that this is particularly apparent in the context of a life crisis and when symptoms can be visualised.

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Table 1: Participants' characteristics

Name	Sex	Age	Eth	Wt. loss	On drug	Time on drug	Adher	Life event	Visual Side Effects	cause
Marie	F	62	W	None	Yes	18 mths	Yes	No	Yes	Bio
Agnes	F	61	B	None	Yes	12 mths	Partial	No	No	Beh
Linda	F	51	W	Large	Yes	5 mths	Yes	Yes	Yes	Beh
Frances	F	57	W	Reg-ained	Yes	28 mths	Partial	No	Yes	Bio
Pat	F	34	W	Reg-ained	No	3 mths	Yes	No	No	Bio
Peter	M	49	W	Large	Yes	8 mths	Partial	Yes	Yes	Beh
Kate	F	33	W	Too recent	Yes	2 wks	Partial	No	Yes	Bio
Marion	F	40	W	Large	No	2 yrs	Yes	Yes	Yes	Beh
Roger	M	58	W	Large	Yes	1 yr	Yes	Yes	Yes	Beh
David	M	47	W	Large	No	6 yrs	Yes	Yes	Yes	Beh
Tanvir	M	44	A	Large	Yes	5 yrs	Yes	Yes	Yes	Beh
Matthew	M	43	W	Large	No	5 yrs	Yes	Yes	Yes	Beh