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WORKING WITH A MAN WHO HAS PRADER-WILLI SYNDROME AND HIS SUPPORT STAFF USING MOTIVATIONAL PRINCIPLES

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Abstract. This paper describes an intervention with a man who has Prader-Willi Syndrome (PWS) and mild learning disabilities in a residential setting. PWS is a chromosomal disorder that is characterized by a wide range of behavioural characteristics including overeating and challenging behaviour. The intervention was based on a range of principles derived from a motivational interviewing approach, which were embedded in a broader behavioural framework that was designed to assist in weight reduction and reduce challenging behaviour. Records of weight and challenging behaviour kept over time suggest that the approach had relatively little impact on overall weight. However, levels of challenging behaviour were reduced quickly and have been maintained at a stable and lower level. Weight has also been maintained at a reasonably constant level without confrontation with staff or excessive restrictions on the individual concerned. Relationships between the individual and staff in the home also improved over the course of the intervention.

Keywords: Motivational interviewing, motivational approach, Prader-Willi Syndrome, learning disability (intellectual disability), support staff.

Introduction

Prader-Willi Syndrome (PWS), first described in 1956 by Prader, Labhart and Willi (see Clark, Boer, & Webb, 1995), is associated with chromosomal deletions on chromosome 15. PWS is characterized by a wide range of behavioural characteristics; initial recognition can be through extreme floppiness, a particular facial appearance, and immature gonadal development, all apparent at birth (Waters, 1997). This can be associated with a failure to thrive in early life. However, from early childhood a marked increase in appetite and over eating is evident. There is evidence to suggest that the normal satiety response is both

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impaired and delayed in people with PWS (Holland, 1998). It seems that if people with PWS are given free access to food then their weight is likely to increase (Dykens & Cassidy, 1996; Holland, Treasure, Caskeran, & Dallow, 1995) and life threatening obesity can result. A number of authors have also indicated that PWS is associated with a range of challenging behaviours including tantrums and rages as well as abnormalities of sleep (e.g., Clarke, Waters, & Corbett, 1989; Dykens, Hodapp, Walsh, & Nash, 1992; Holland et al., 1995). Later in life, the presence of varying degrees of learning disability, delayed or immature secondary sexual development, and immature emotional and social abilities all become apparent (Waters, 1997).

Although there are no specific treatments available to assist people with PWS, an awareness of the difficulty of overeating and potential obesity has led to recommendations that unsupervised access to food should be avoided. Waters (1996) recommends a number of restrictions including: locking the doors to the kitchen and bedrooms, all food storage areas to be lockable or in secure areas, the proximity of food shops and outlets need to be considered and the possible installation of pressure pads or light sensitive alarm systems. Controlled access to food is now much more commonly used with children who have PWS (Holland, 1998), but the long-term effects of this strategy are yet to be evaluated. The moral and ethical implications of such a management strategy also need to be considered. The appetite suppressant, fenfluramine, has also been used with people who have PWS in a double blind crossover trial (Selikowitz, Sunman, Prendergast, & Wright, 1990). However, the main effect of this treatment was to reduce levels of challenging behaviour rather than have specific effects on weight reduction.

Holland (1998) has recently suggested a conceptual model to aid the development of management strategies to prevent obesity in people with PWS. This not only suggests supervision and medication as potential treatments but also cognitive behavioural interventions. The present paper considers the development of such a strategy, using ideas from motivational interviewing, a technique usually associated with brief individual therapy, but in this case applied over a period of months via a staff group in co-operation with an individual with PWS.

Motivational Interviewing

Motivational Interviewing was first described by Miller (1983) as a treatment for problem drinkers. It has been developed over recent years and there is now good evidence to suggest that it is an effective treatment for this group (Miller, Benefield, & Tonigan, 1993; Brown & Miller, 1994). However, it has also been used in a number of other applications (Miller & Rollnick, 1991). Motivational Interviewing has recently been defined as ‘‘a directive, client-centred counselling style for eliciting behaviour change by helping clients to explore and resolve ambivalence’’ (Rollnick & Miller, 1995) where the examination and resolution of ambivalence is its central purpose, and the counsellor is intentionally directive in pursuing this goal. This definition has further been elaborated by Rollnick and Miller (1995) to include a number of key points that encompass the spirit of motivational interviewing: (1) Motivation to change is elicited from the client, not imposed from without. (2) It is the client’s task, not the counsellor’s, to articulate and resolve his or her ambivalence. (3) Direct persuasion is not an effective method for resolving ambivalence. (4) The counselling style is generally a quiet and eliciting one (with direct persuasion, aggressive confrontation and

argumentation being the conceptual opposite of motivational interviewing. (5) The counsellor is directive in helping the client to examine and resolve ambivalence. (6) Readiness to change is not a client trait, but a fluctuating product of interpersonal interaction. (7) The therapeutic relationship is more like a partnership or companionship rather than expert/recipient roles.

Some basic techniques used in the implementation of a motivational format include: developing empathy, warmth, genuineness and unconditional positive regard; avoiding arguments; rolling with resistance; working with discrepancies and supporting self-efficacy (Miller & Rollnick, 1991). Examples of the way these concepts were used will be described later.

The difficulties presented by the desire to overeat in people with PWS may be seen as to some extent analogous to an addictive process. While it is unrealistic to suggest that overeating can be eliminated totally because it may be the effect of a genetically determined syndrome, as with addictive behaviours, a client may approach an initial session after advice from significant others to stop completely. It is likely, however, that the client will be aided to explore whether it is more realistic and/or appropriate to reduce use rather than stop altogether, and for the person with PWS this should be a possibility.

Even though motivational interviewing is a directive approach, the counsellor may help the client order and appraise a complex array of information in a way that is understandable to them. Such an approach may also help clients come to their own conclusions at a pace appropriate to their own needs. Both of these latter points may be particularly useful to the person with PWS and a learning disability. There are also instances where clients with learning disabilities are said to lack motivation or insight, and this approach may provide a powerful tool to develop both of these facets within an individual.

Introduction to the client and setting

The client is a 29-year-old man with a mild learning disability and Prader-Willi Syndrome. Insulin-dependent Diabetes Mellitus was diagnosed in late 1994. He has lived in an NHS Trust community home with one other gentleman (non-PWS) with 24-hour support from a staff group since moving from his parental home 4 years prior to the start of this study.

This gentleman, like many other individuals with PWS, was frequently seeking opportunities to obtain and eat food. This included removing and consuming discarded food from bins and stealing items and money. He received a police caution after evidence linked him to the theft of money in the community. He would also collect money from neighbours for ‘‘staff leaving’’, ‘‘deceased relatives’’ or ‘‘for food because the staff didn’t give him any’’. At times he had stolen from children, the elderly and others with learning disabilities in order to obtain food.

He also presented with a large number of challenging behaviours including verbal and physical abuse towards others. These had resulted in both temporary and permanent exclusions from clubs, activities and educational placements in the community. These incidents had at times been very severe: after one particularly serious incident, when he threatened staff with a knife and placed a belt around another staff member’s neck, consideration had been made by a multidisciplinary group about the implementation of a Mental Health Act Section. Concern over his increasing weight had also led to the consideration of a section. However, this approach was rejected.

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Nevertheless he had many appropriate social skills and considerable independence. He had a structured and full week including work, education and leisure activities, during which he also has plenty of opportunity to assess the community independently. He was also in receipt of a weekly allowance that was given to him upon request. On receipt of his allowance, he would travel to a local town independently by bus and often purchase food items.

Baseline recording and rationale

Records were kept by direct care staff as part of their general routines. These included regular monitoring of weight. However, at times he would not always comply with requests to use the scales. Where possible, the same set of scales was used in the same location. He was also weighed at the same time of day and requested to wear a similar amount of clothing. Staff also recorded incidents of challenging behaviour on charts that requested information about the behaviour with associated antecedents and consequences. A range of behaviours was recorded including extended verbal abuse, stealing, property damage and physical assault. To try and ensure a degree of consistency in selection of incidents recorded the house manager and a clinical psychologist reviewed records over time prior to inclusion in the data presented.

During the period of baseline recording it became apparent that staff could help this man to keep his weight at a reasonably stable level (116–122 kg). However, he was only 1m 58cm tall and to keep him in this weight range they had to exert considerable control over his environment by ensuring access to food was strictly monitored and limited. This would often lead to incidents of physically and verbally aggressive behaviour, which occasionally resulted in the client being able to access food. Stealing or begging for money would also often result in him being able to obtain food. These incidents would often lead into further conflict with staff. In this way, the client's challenging behaviours may have been intermittently reinforced. The relationship between the client and staff within the setting had also become strained as a result of a number of factors including lying, stealing, aggression and a perceived need to continually exercise control on the part of staff. When these factors were combined with the difficulties associated with obesity of the client, interpersonal relationships in the home were strained. Towards the end of the baseline period, it was becoming more difficult to help the client maintain a stable weight, with increases being noted and incidents of challenging behaviour appeared to be increasing in frequency. As a result of these circumstances and combined with the issues of individual rights, independence and self-determination, it was felt to be imperative to develop a more collaborative regime between the client and his carers.

Implementing a motivational approach

In order to implement a motivational approach into the setting a number of steps were taken. A primary facilitator was chosen from within the staff group; in this instance the manager of the group home was chosen for a number of reasons. The manager had an interest and some knowledge of motivational interviewing, and as it was a new approach it was felt the manager could more easily enact the necessary changes. The client also recognized the influence of the manager within the home. The primary facilitator worked individually with the client on a regular basis; however, efforts were made to disseminate the appropriate skills

to other members of staff and as other members of staff started to apply these principles in their practice it became possible for him to withdraw and monitor progress.

Any system that staff perceived as being imposed was unlikely to work, so discussions were held with staff over some weeks prior to implementation. Initial ideas were introduced in staff meetings and through changes in the structure of staff supervision. For example, supervision was used to emphasize a counselling approach, with the use of empathy, warmth, genuineness and positive regard being seen as important in both relationships with the client and staff. Supervision was also used to encourage activities and projects for staff that enhanced their self-esteem and in recognition of this aided an exploration of self-esteem in the client. New activities also provided opportunities to praise the client. Indeed, staff were encouraged to praise any behaviours that suggested that the client was accepting more responsibility for his own well-being and behaviour, particularly in relation to his diet. A non-confrontational approach was emphasized throughout the staff group. Changes in staff practice were also introduced through direct staff training, modelling by the facilitator and discussion within the staff group. Relevant literature was also made available within the setting. In this way, a basic behavioural framework was developed, which rewarded desirable behaviours, such as keeping to menu plans and participating in exercise, whereas it was made clear that challenging behaviours, such as stealing, were inappropriate. However, staff were encouraged to minimize interactions with the client about these incidents. A variety of other techniques were introduced to routines and practices, some of which are detailed below.

Empathy, warmth, genuineness and unconditional positive regard

The facilitator emphasized the importance of these therapeutic ideas to the staff group. It was found that helping staff to develop a thorough knowledge of PWS and an awareness of the client's background and culture were important in providing an effective foundation for understanding the client. This was partially addressed by introducing a life storybook that acknowledged the client's autonomy and independence (Hewitt, 1998).

Training in counselling skills and techniques were introduced for all staff to encourage the use of reflective practice (Palmer, Burns, & Bulman, 1994). The use of concepts of reflective practice was also encouraged in staff record keeping. Developing trust has brought emotional and historical disclosures with the revelation that there was considerably delayed genetic counselling (in this case he was actually 12) and it has been possible to discuss the effects this has had on the client.

Avoiding argumentation

Experience had indicated that although the client may initially disagree, he may return to a discussion hours, or even days, later. It was clear from an analysis of incidents of challenging behaviour that when discussions became arguments the client no longer listened effectively (nor, indeed, did the staff). Staff were encouraged not to argue with the client and disengage from disagreements as soon as possible after they started. They were then encouraged to wait for a period until it was felt appropriate to ''plant the seed'' in a calm, non-confrontational manner. These moments were recorded in a factual way to aid a consistent approach and develop understanding of the client's difficulties within the staff group. On

one occasion, a few months after adopting this approach, it became apparent to staff that additional and inappropriate food had been consumed. Staff suggested that concern over his immediate health could be addressed if he were to check his blood glucose levels. He refused to co-operate stating that it was not necessary. Staff did not continue the conversation. Ten minutes later he requested the necessary monitoring equipment. He was praised by staff for this and went on to check his blood glucose levels. These were found to be slightly elevated. An appropriate course of action was then considered in collaboration with staff. This approach both avoided an argument and resulted in an educational opportunity. Subsequently, he has asked for equipment to check his glucose levels when he feels that he may have eaten something detrimental to his health.

Rolling with resistance

As when engaged in arguments, it is relatively ineffective to meet resistance to change head-on, resistance being identified when discussions became arguments and when interruption, objections and denials occur. These situations were approached by staff reflecting back to the client what they were saying and shifting the focus (within the context of the area discussed) while at the same time as emphasizing personal control and choice.

Prior to developing a motivational approach staff had reluctantly taken the decision to monitor the contents of the client's room in order to try and reduce the possibility of him eating additional and inappropriate food. With the advent of the new approach, the facilitator discussed the possibility of the client self-reporting incidents to staff if he consumed additional food. This was initially resisted in the context of his personal rights and privacy. The facilitator ''rolled'' with this, emphathizing with his concerns and feelings. The conversation then developed into ways in which he could ensure that staff would not enter his room. Together, it was concluded that food wrappers would be placed in a bin outside of his room so that staff could monitor any additional food intake while respecting his privacy. This procedure has successfully remained in operation for over a year.

Working with discrepancies

Facilitating an individual to note any discrepancy between their stated intent and the reality of their present position and behaviour can lead to a sense of discomfort with the situation motivating self-elicited change. For example, this individual leads an active life but has experienced health problems due to excessive weight gain. To manage this problem more effectively, we were able to draw up a plan with him that included structured exercise and a more appropriate food intake in order to reach a goal the client himself wished to attain. There were also opportunities to create a situation within this context to motivate him. For example, he was frequently in possession of money, which he would often spend on food, but staff were encouraged to be creative in offering opportunities to purchase alternative activities (such as excursions or going swimming) or non food items that he might desire.

Opportunities for creativity

Within the spirit, principles and philosophy of motivational interviewing there are substantial opportunities for creativity. One technique used with clients who had addictive behavi-

ours but who were reluctant to engage involves the therapist presenting him or herself as incompetent, new or under pressure from superiors, thus requiring ''help'' from the client. This approach proved particularly useful when the client exerted pressure to eat inappropriately, regardless of the consequences. In this case, conversation focused on the facilitator's concerns about senior management's continuing support for the new regime should the client's health deteriorate through what management would perceive as a ''lack of duty of care''. In this instance, it was possible to discuss the value of the partnership that had been forged, highlighting how things had been previously with severe arguments, perceived lack of choice, and independence. The interchange concluded in an agreement that ''we will show them! We can do this!'' Unsolicited disclosures of additional food intake, request for exercise opportunities and a re-assertion of self-control followed this later in the day.

Supporting self efficacy

For the individual to believe in the possibility of change, and to take on a broad personal responsibility for choosing and carrying out effective change, a number of projects were introduced. For example, involving the client in a ''food team'', which looked at nutrition and diet for everyone in the house, and working with the client to improve the decoration and furniture in his room.

Staff helped by listening effectively, assuring the client's concerns, needs and wishes are attended to as soon as possible, thus maintaining a partnership based on trust. They were also encouraged to be creative in indicating the range of alternative approaches available and providing support. Staff were also involved in creating and adapting care plans that involved the client but which at the same time became motivational statements for him to refer to.

Providing clear and consistent feedback regarding his progress was also important. For example, to take responsibility for his weekly weighing (with reinforcements when weight loss occurred) and taking blood samples for daily glucose levels (taken independently to avoid thoughts of ''electronic spying''). Staff provided feedback on observed mobility and stamina during exercise (primarily swimming and badminton), and encouraged a free dialogue about the types of food he purchased. Feedback was seen as vital both for the individual and staff in order to maintain motivational intent.

On a practical level, the client's motivated intent to change has elicited disclosures regarding additional food intake and these help staff to modify planned menus with full co-operation. For the staff, developing the ability to negotiate effectively has enhanced the concepts of partnership and alliance with the client.

Outcome and conclusions

Throughout the intervention, house staff kept records of both the weight of the client and levels of expressed challenging behaviours. During the baseline period of a year his weight fluctuated from 122kg to 115kg in the first 6-months with a rise to 127kg at the start of the intervention. Initially, there was an increase in weight associated with implementation of the motivational approach to 128kg, followed by a reduction to between 120 and 115kg. This pattern suggested there was little overall impact on weight. However, it must be noted

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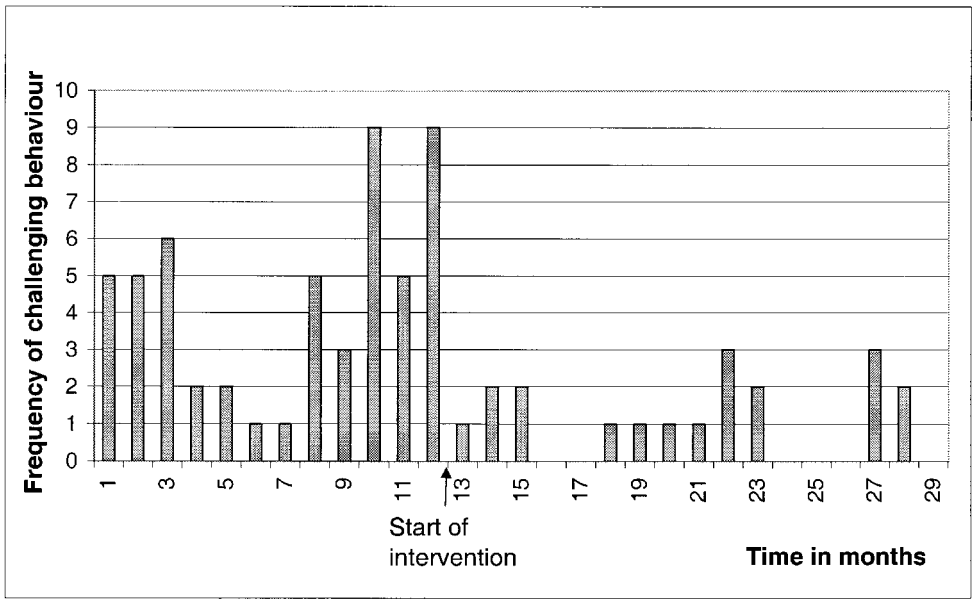

Figure 1. Incidents of challenging behaviour each month

that the staff felt that the previous regime that had maintained this weight had been considerably more restrictive and confrontational than the motivational regime.

Incidents of challenging behaviour were also monitored over time (Fig. 1.). Twelve months of data are provided prior to intervention, over which time there was an average of 4.4 incidents of challenging behaviour each month. On introduction of the motivational approach there was a dramatic reduction in the number of incidents of challenging behaviour to 1.1 incidents per month. To assess the impact of the intervention, an interrupted time series ARIMA (Autoregression in moving average) analysis was used. A permanent abrupt impact was employed to model the intervention effect with a lag of 1 to model the autocorrelation in the data series (no moving average term was incorporated). A permanent abrupt impact pattern implies that the overall mean of the time series shifted after the intervention; the overall shift is denoted by the parameter *W* in Table 1. As can be seen in Table 1, the intervention resulted in a significant and permanent reduction in challenging behaviour (w= –7.59, t=–2.80, p=.009). These observations provide evidence for lower levels of challenging behaviour and suggest that a degree of weight control is being achieved with less confrontation and restriction. The client has also achieved effective control of his diabetes, with much of the responsibility for monitoring being dealt with by him.

Table 1. Interrupted time series ARIMA analysis

		Std. Error	*t* (27)	*P*	Lower 95% conf	Upper 95% conf
p(1)	.9672	.0691	13.9873	.0000	.8253	1.1091
W	–7.5869	2.7126	–2.7969	.0093	–13.152	–2.0211

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These observations suggest that the approach had little effect on the weight of the individual in this study. The desire to eat may well be an integral part of the behavioural phenotype of PWS. However, challenging behaviour reduced very quickly when staff changed their approach. This suggests that challenging behaviour could be a product of the setting events encountered by individuals. That is, if you are faced with external restriction (of food), then without appropriate assistance, challenging behaviour is likely to result. This situation is much less likely to occur if staff are instructed not to directly confront and an appropriate environment is constructed to encourage self-control.

There are limitations to this study, the most obvious being that it is a single case design with no element of reversal. Clearly, this individual may be atypical in some way and the development of this approach with others will be necessary, if efficacy is to be confirmed. The intervention has also not addressed the issue of weight control as well as may have been hoped. Dramatic weight reduction has not been achieved and the client is still considerably overweight, even though his weight is stable. However, there has been a marked reduction in challenging behaviour.

The specificity of the approach needs to be considered, as it is impossible to determine which aspects of the approach were responsible for the change. Were all of the techniques necessary, or could a reduced subset be sufficient for change? For example, would a client-centred counselling approach be sufficient for change or was change due to the increased structure and input that was provided while implementing the approach? Indeed, one could probably construe many of the developments described without using the motivational paradigm by using descriptions more usually associated with behavioural work such as positive programming and reinforcement strategies. The approach could be conceptualized as a non-aversive behavioural approach (McDonnell, Cleary, Reeves, Hardman, & King, 1997). Clearly, this difficulty limits the conclusions that can be made from this paper and suggests the possibility of further research using more rigorous designs and with larger samples.

For the staff the new structure has emphasized the advantage of a collaborative culture rather than crisis response and confrontation. This has resulted in a considerably improved quality of life for the client, particularly in terms of personal freedom and access to the community. As a result, the intervention is not subject to some of the ethical concerns posed by limiting access to food. The intervention has also improved the working conditions of the staff, both in terms of providing greater opportunities for working together and reducing the threat of violence and injury.

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