I’m sure the gardeners amongst us will know what I mean when I say ‘dead wood’. I’m also certain that ABBA fans can sing SOS. So, if nothing else, Gardeners World is in a pair of Knowing Me, Knowing You safe hands. But, all of this frivolity reminds me that there is a stack of stuff in my life that requires cutting out in order to Save Our Souls. For some time now I’ve been intending to do some trimming of my own metaphorical garden, but have, due to laziness, tended to opt out. I prefer to call it minimal interference and like much of the Journal of Health and Social Care Improvement’s approach, allow contributors space to grow, emerge awkward opinion and tackle issues beyond the ‘what you see is what you get’ ethos standards of many on-line journals. You see, with a sharp sickle in my editorial right hand I am more than able to scythe down opinion but that’s not what the Journal of Opportunity does. In fact, here on the editorial board, we prefer to don white flares, glittery high-heels and repeatedly pout at one another whilst recognising that taking a chance is better than a winner taking it all. So we hope to encourage more of you to send us your articles. Anyhow, all this wittering and chopping brings us to this edition.

In this forest, there is plenty on offer from a broad multidisciplinary contribution. The wise words of Carol Cullen, Wendy Nicholls and Magi Sque keep ahead the Waterloo that is obesity, whilst Jonathan Beckett focuses on the serious issue that is the Mama Mia of other eating issues known as Prader–Willi Syndrome. These original research articles are not the only Name of the Game as they are joined by a Super Trooper article contributed by Emma Dudzinski who writes quite rightly about the needs of a growing elderly population. In between we have a commentary by Anita Z Goldschmied who, in her usual manner, makes comment as to how no one ever hears the tree fall in the woods. Now, if all of this ABBA revivalism has got you wondering about tentative connections then look no further than the link below and answer this. How come Benny Anderson has his back to the rest of the band? Answers to appear in the next edition, but we reckon its no walk in the woods, especially if it’s not dead.

Click here for ABBA SOS (1975)
The emergent self: a grounded theory of weight loss maintenance
Carol Cullen*, Wendy Nicholls, Magi Sque
Department of Psychology, University of Wolverhampton,
Nursery Street, Wolverhampton, U.K. WV1 1AD

Abstract
This study developed a substantive theory to explain maintained weight loss. Individuals who live with the classification of severe obesity often experience physical and psychological ill health and the frequency and severity of comorbidities make weight loss increasingly difficult. Whilst short-term interventions in treating obesity are successful, long-term maintenance of weight loss shows limited success. Participants began losing weight from a B.M.I. of 35 or above, reached their goal weight and maintained this weight loss for at least one year. Seven semi-structured interviews were carried out and analysed using Charmaz’s (2006) grounded theory approach.

Data was analysed and a substantive theory of ‘Emergent Self’ was constructed, which explained participants’ views and feelings. The emergent self was the most pervasive core category from seven categories; ‘Normalizing’, ‘Controlling’, ‘Isolating’, ‘Seeking’, ‘Gaining’, ‘Analysing’ and ‘Choosing’.

Findings revealed that as participants experienced a process of psychological awareness within a favourable environment their reliance upon food for emotional coping and avoidance reduced. The environment provided; hope for recovery, identification with others, openness and honesty to share, self-acceptance and access to a non-judgemental supportive community of like-minded individuals. The participants facilitated a life-long way of achieving maintained weight loss. These findings can be used to inform weight management programmes.

Keywords: Maintained weight loss, Severely Obese, Weight management, Grounded theory, Substantive theory

Introduction
Obesity is very prevalent in today’s society on a worldwide scale. Compared with metabolically healthy normal-weight individuals, obese persons are at increased risk for adverse long-term outcomes even in the absence of metabolic abnormalities (Kramer, Zinman & Retnakaran, 2013). Obesity increases the chances of serious mental and physical conditions (Must, Spandano, Coakley, Field, Colditz & Dietz, 1999) including; depression (Faith et al, 2011), high blood pressure (De Pergola, Nardecchia, Guida & Silvestris, 2011), high cholesterol (Andersen, Kendall & Jenkins, 2003), diabetes Type 2 (Kyrou & Kumar, 2010), heart and kidney disease (Liu, von Deneen, Kobeissy & Gold, 2011), stroke (Toss, Lindahl, Siegbah, & Wallethin, 1997) and respiratory disorders (Jubber, 2004). The frequency and severity of comorbidity increases further for those individuals living with the
classification of severe obesity, making weight loss increasingly difficult through poor mobility and a higher risk of mortality (National Institute of Clinical Excellence [N.I.C.E.], 2006). Whilst society adjusts to individuals with severe obesity, the implementation of wide scale factors contributing to the amelioration of this condition appear limited (National Obesity Observatory [N.O.O.], 2009).

A healthy diet and increased exercise are considered to be the basis to weight loss yet attrition rates are high on weight management programmes implementing these (Grave, Suppini, Calugi & Marchesini, 2006; Teixeira et al, 2004). The reasons for this attrition call for further investigation. As weight and comorbidities increase NICE (2014) guidelines suggest that individuals should be referred to a specialist, Tier 3 weight management programme to receive medical, psychiatric, psychological and dietary assistance in addition to exercise advice. Whilst this approach appears comprehensive NHS England, 2014 state that the clarity around the service that each NHS practice implements and the efficacy of Tier 3 specialised obesity services are variable, with the absence of such services in many areas. For those individuals who have a B.M.I. of ≥ 35 with comorbidities bariatric surgery is recommended. Surgery itself presents risks (Apovian, Garvey & Ryan, 2015), however consideration is being given to lowering the threshold for bariatric surgery to a BMI of 32 (N.I.C.E., 2014). It is of significant importance to remember that obesity is itself primarily a preventable condition and when we consider that people are spending a lifetime experiencing obesity and the negative consequences it brings to the individual it is vital to understand more about achieving non-surgical long-term weight maintenance (Wadden & Butryn, 2003; Wing & Phelan, 2005).

A meta-analysis of nutritional and behaviour-focused weight management interventions suggests that diet and exercise remain largely unsuccessful with half (Wadden & Butryn, 2003) to three quarters (Anderson, Konz, Frederich & Wood, 2001) of participants usually regaining their lost weight within five years. The rationale for individuals being unable to sustain their weight loss long-term remains unclear. Theoretical explanations have been presented which have focused on biological, behavioural and psychological determinants (N.O.O., 2010). Contributory factors to obesity from a biological perspective include having a genetic disposition (Nammi, Koka, Chinnala & Boini, 2004; Wilding, 2011); damage to a particular area of the brain which controls satiety and hunger signals (Thaler et al., 2012); an instinctive biological drive - eat to survive (Van Buren & Stinton, 2009). Many people may originate from a long line of descendants who have been obese or severely obese and whilst a biological factor may be an element of their obesity, this may also be explained as a learned behaviour dependent upon cultural, environmental or emotional factors (Collins & Bentz, 2009). Schachter's (1971) externality theory of obesity suggests that some individuals are hypersensitive to external food-relevant stimuli, while being hyposensitive to internal signs of hunger and satiety. Individuals therefore respond impulsively to the sight or smell of food which can be particularly detrimental in an abundant, high-calorie obesogenic environment. High external eaters have been identified, through the use of neurological mapping of the brain, in producing strong cravings in response to exposure to food which encouraged overeating (Nijs, Franken & Muris, 2009). Similar activation of the brain area has been identified in substance dependent patients to indicate cravings (Field, Munafo & Franken, 2009). With such a strong biological or behavioural instinct to eat when high-calorie food is readily available it is understandable that individuals find it
challenging when asked to join a weight management programme to alter and reduce their eating. Another theory to explain the failure of maintaining long-term weight loss focuses on restraint theory which suggests that the individual uses cognitive control to significantly reduce food consumption. This process can be maintained in the short-term whilst supported by a weight management programme but is difficult for individuals to maintain long-term (McGuire, Wing, Klem & Lang & Hill 1999). An explanation for this failure to achieve maintained weight loss has been attributed to individuals requiring food as a means of affect regulation (Zijlstra et al, 2012) to help cope with various kinds of psychological stressors (Buckroyd & Rother, 2007). When this coping mechanism is withdrawn by changing the individuals diet/eating behaviour without addressing the psychology of what food means to each individual it is too difficult to sustain long-term. This perceived failing from those who are not successful in altering their food intake can result in greater psychological ill health (Miller & Jacob, 2001). Bi-directional associations with obesity and mental health have been made (N.O.O., 2010). Obesity has been linked to depression (Cunningham et al, 2012), anxiety disorder (Toups et al, 2013), psychosis (Wilding, 2011), bipolar disorder (McElroy & Keck, 2012), and post-traumatic stress disorder (Pagoto et al, 2012). Obesity has also been linked to having an insecure attachment (Mazzeschi et al, 2014) and a traumatic childhood (Hughes, Power, Fisher, Mueller & Nicklas, 2005). An individual’s propensity to be isolated and sedentary when experiencing mental ill health, coupled with side-effects of medication which often increase weight, creates a cyclical pattern that is difficult for the individual to break but some individuals have achieved breaking these cycles (N.I.C.E., 2014). With an influence from positive psychology this research looked at what facilitated successful individuals to lose and maintain their weight from being severely obese. In order to obtain this in-depth, ideographic information of each individual’s perspective as well as seeking to obtain a substantive theory of maintained weight loss; Charmaz’s (2006) grounded theory was used.

Methods

Participants

Ethical approval was obtained from The Wolverhampton University Faculty of Education, Health and Wellbeing Ethics Sub-Committee Board and from a National Health Service [N.H.S.] Regional Ethics Committee via N.H.S. Proportionate Review with the relevant N.H.S. Research and Development Site Specific Assessment.

Purposive sampling identified two participants who had finished an NHS weight management programme and one individual who attended Overeater’s Anonymous [O.A.] with two further participants from O.A. via snowballing effect. Two further participants were identified through the researcher’s word of mouth. The initial inclusion criteria looked for participants who had maintained an intentional weight loss of at least 10% of their original weight for at least one year. The criteria was tightened following four interviews, to participants who had reached their goal weight and maintained that weight for at least one year. It was identified that participants with 10% weight loss were found to be fluctuating in weight or were still losing weight and therefore were not keeping an existing state/maintenance of weight loss.

Recruitment for the two N.H.S. participants entailed sending a recruitment pack to the N.H.S. Service. The Service sent out a participant pack to 27 individuals who met the initial inclusion criteria. The pack contained a letter of introduction with contact details of the researcher and an information
sheet explaining the aims of the study. The participants obtained via word of mouth, one of which was an O.A. member, were passed the researcher’s contact details. When they made contact they were then forwarded the introductory letter, information sheet and consent form. Recruitment extended to advertising an A4 poster in gyms, health centres, emailed to sports centres, sports clubs, B-EAT website and advertised in a newspaper. The last three participants were recruited from O.A.; study information/contact details were circulated to their branches.

A total of seven adult participants took part in this study; three men and four women aged between 31-61 years of age (mean = 49). Table 1 provides a summary of the participant’s demographic information detailing weight/height and BMI and comorbidities at the time of commencing weight loss. One participant had a BMI of 31.6 at the start of her weight loss therefore did not reach the inclusion criteria. This participant was included because she had managed to maintain a healthy weight for 18 years whilst suffering from depression. All identifiable information was changed throughout the study to ensure anonymity of participants. O.A. participants wanted it known that it was their personal view they presented not those of O.A.

Semi-structured interviews were conducted after obtaining informed consent and completing the data collection form; the first four interviews were at each participant’s home. The researcher adhered to a lone-worker’s policy. A further interview was carried out by telephone and the last two were by Skype (non-video), due to the distance involved in achieving face to face interviews. Interviews lasted between 43 and 93 minutes and were recorded on a hand-held dictaphone. An interview schedule was used as a guide to ensure the objectives of the study were met whilst using open ended questions to encourage participants to talk openly about their experience of achieving maintained weight loss. Each interview was transferred to a security coded laptop and transcribed verbatim by the first author as soon as feasible. Interviews were listened to at least three times to ensure an accurate transcription and to become immersed in the data. Pre and post interview reflective field notes were made to provide context for the interview and to record impressions and interactions of the participant and researcher. A debrief sheet was given to the participant at the end of each interview which detailed the aims of the study along with contact details of national charities related to eating disorders and listening services.

Data was analysed using Charmaz’s (2006) grounded theory with the aim of obtaining a substantive theory to contribute towards future weight loss interventions. Analysis involved gerund (line by line) initial coding to ensure the process from the data was obtained. Initial coding was then elevated to form focused codes and then categories. Memoing was recorded throughout each stage of the analysis ensuring openness of the researchers’ thought processes and interpretations. Constant comparison of all the data/focused codes/memoing ensured that the categories developed could be identified as grounded in the data (Elliott & Lazenbatt, 2005). Analysis revealed seven categories which formed a storyline of maintained weight loss. The seven categories integrated to form an eighth core category of ‘Emergent Self’.
Theory of Emergent Self showing the storyline and category integration; ‘becoming prominent the conscious knowledge of one’s own character, feelings, motives and desires’

![Figure 1 Storyline of Weight Maintenance](image)

**Results**

The ‘Emergent Self’ showed the individual becoming consciously aware of their own character, feelings, motives and desires. This psychological self-awareness placed the individual in a position of being able to understand their response to difficult emotions and to begin to address these emotions in a more positive way so that they did not need to avoid them by using food.

The storyline focused on the underlying process that was occurring for the participants as they achieved maintained weight loss and the factors which influenced and prevented this process. The categories identified are discussed along with excerpts from the participants’ interviews to illustrate the construct of their experiences to maintained weight loss.

**Normalizing – Responding to patterns of behaviour in childhood**

The majority of participants were able to identify patterns of emotional and behavioural responses to food which they first experienced in childhood. Examples included; being given large portions as a child because their parents were overcompensating for their own lack of food in childhood, having to clear their plate of all food, having second helpings therefore not learning satiety or overriding hunger signals. Patterns of emotional associations with food focused on; one participant who was living in an abusive family and secretly being given sweet food to make everything seem better. She continued using sweet food in this way when she was taken into care. Another participant was shown love from her parents through food rather than verbal and physical affection;
“Food was very important for our family...like the currency; you know it was like love on a plate really.” (Claire, Line 122)

Logical reasoning is often used to reduce food intake and/or change to healthier food in weight management programmes but it is questioned whether the strength of the emotional attachment to a type of food is addressed.

“I knew that whatever happened to me if I could get something sweet to eat I would be OK.....calmed me down....” (Claire, Line 129)

This view was expressed by Claire when she reflected on attending a slimming club;

“When I look back now it was crazy, there was no psychological feeling component to why we’re we’re all fat, it was just about well if you just do this with your chicken satay or whatever it was, it was just crazy superficial talk ......” (Claire, Line 195)

**Controlling – Avoiding thoughts and feelings**

Participants spoke of difficult life events and how they responded to them with food. Charles grew up believing you could buy love, as an adult he got into debt and he identified how he would use food to avoid his negative emotions day or night;

“I’ve stuffed kinda feelings down you know” (Charles, Line 454)

“I used to find that if things are blocking my head if I got up during the night for the toilet or anything like that I’d visit the fridge” (Charles, Line 631)

This study was able to compare those who had reached their goal weight to those who had lost 10% of their weight and were still fluctuating. Those who had lost 10% of their weight spent a lot of time creating an external focus; measuring and recording weight, monitoring exercise and food and measuring portion sizes. Participants who had achieved maintained weight loss identified this external focus as something they also used to do which became a barrier to achieving maintained weight loss.

“I mean I did an awful lot of overeating...I also did an awful lot of thinking about it too...or planning how I was going to lose the weight, I spent a lot of mental energy on all of that so the fact that I don’t have to do that anymore.....I live differently.” (Claire, Line 504)

They identified that the internal process of being self-aware; what they were thinking, feeling and ultimately how they were behaving was what facilitated their maintained weight loss. They had to learn how to manage difficult emotions without the use of food or avoiding through the use of external focus.

**Isolating – Feeling ‘abnormal’ and alone**

Being unable to manage their emotions and having to use food to help avoid these feelings was found to leave the individual with a wish to avoid being with themselves; they did not like the person they had become. Linda shows how she would use substances to avoid having to be with herself;

“I just loved eating and loved food and then found alcohol, I loved alcohol and I couldn’t get enough of that. Do you know... it was always like something to make me feel different about myself....a sense of just not being able to sit with yourself....you have to do something to try and not sit with yourself.” (Linda, Line 534)

This negative self-image was shown to increase the need for using food, or any substance to such a
degree that the individual felt to have lost control over themselves and the substance. This created a negative cycle which the participants found very difficult to move away from and resulted in isolation and in some cases poor mental and physical health.

Participants spoke of negative cycles which were exacerbated by attending slimming clubs where maintaining control and record keeping were encouraged and the occasional treat was monitored. Participants who had achieved maintained weight loss found that they had to abstain from the food they could not eat in moderation; in the same way that an alcoholic would abstain from alcohol. Participants who attended the weight loss programmes were able to lose weight in the short term but found that the weight would return after leaving the programme.

“All the time I lost weight I would then put that weight back on and I always put on more, um so in some ways I sort of dieted myself up to twenty two and a half stone” (Linda, Line 112)

This cycle left participants feeling immense shame and self-blame choosing to isolate themselves. Participants had a feeling of being abnormal and separate from the rest of society. Their shame led them to secrecy around their eating which often made seeking help difficult to do.

**Seeking – Reaching levels of desperation in wanting help**

“All it was so secret, I was so ashamed. The sense of shame I had was huge so to go to a normal doctor I just don’t know how they do that but some people do but I couldn’t do that.” (Claire, Line 587).

**Gaining – Obtaining self-acceptance and self-awareness**

Lacking awareness of why the individual was overeating prior to successful intervention was prevalent in all of the participants’ interviews. Being in an open and supportive environment allowed the participants to identify with others, obtain a sense of inclusion therefore no longer feeling alone or abnormal.

“I was very much a Jekyll and Hyde really I suppose... I’d put on a big front for everybody but inside I was really quite depressed and unhappy but I never let anybody know – I’m much more open and I’m very very different...just much more real I suppose.” (Claire, Lines 548/564)

The participants found that by listening to others talking openly and honestly, they received a sense of hope for a better future around food. They were immersed in a community of like-minded individuals who provided support and acceptance for as long as they required it. Whilst experiencing this support they were encouraged to be autonomous and take responsibility for any decisions they made. As participants achieved positive mental health through self-reflection and analysis, their focus around food changed; they no longer used food as a means of coping or avoiding. They were able to then achieve maintained weight loss and as they recovered they were encouraged to then help others.
Analysing – Looking objectively at your own patterns of thoughts, feelings and behaviours

Participants were identified as journaling daily how they thought and felt which they would then look at objectively. If the participant was unable to see another way of looking at their emotions, possibly due to feeling overwhelmed by them, they could seek support from another individual. The process allowed exploration of themselves on a regular basis to manage their thoughts and feelings. Linda explained that she had always responded to everything with extreme emotion, that there was no middle ground or moderation.

“I felt like everyone else had some sort of instruction manual for life and that I just hadn’t got my copy because I felt very over sensitive very emotional…things just touched me really hard, like very deeply um even as a young kid.” (Linda, Line 518)

Regular monitoring of her emotions prevented them from dominating her life and she was therefore able to live her life more successfully and peacefully. Linda indicates that her main focus was not the weight but more on trying to manage extreme emotion and how it made her feel. Claire also states that weight was not her primary concern;

“It wasn’t just about the weight ever it was about me and inside me.” (Claire, Line 555)

Choosing – Taking it seriously one day at a time

Maintained weight loss requires a life-long approach and cannot be treated in an on-off way. The participants who had maintained weight loss were abstaining from the foods that they could not eat in moderation, a day at a time. This helped the participants stay in the present moment. They reflect daily their thoughts and feelings. Once maintaining their weight they do not dwell on the past or think too far into the future. This helps them cope with the feeling of loss from not having the food they crave in their lives, so that they do not feel overwhelmed.

“If you’re told you have to do you have to stop something for the rest of your life there’s quite a panic…..you must be willing to go to any length which is what I was at the time you know…. That’s every day of the week regardless of birthdays, Christmas or any special events. Never alter, never intend to.” (Charles Lines 62/540)

Abstinence needs constant awareness by the individual; Linda found abstaining from high amounts of sugar in foods very difficult to do because sugar is presented in high quantities in many foods yet it is not obviously apparent. She has to remain constantly vigilant not to trigger her overeating off accidentally.

Discussion and Summary

The aim of this study was to provide insight into the facilitators of maintained weight loss from the perspective of individuals who had severe obesity and now have achieved maintained weight loss at goal weight. Analysis revealed the importance of psychological wellbeing in achieving maintained weight loss and how this can be obtained, by looking at attachment, self-awareness, self-esteem, self-acceptance, affect regulation and reflection. Weight itself became a secondary concern for the participants.

Initially this research questioned whether 10% intentional weight loss for individuals with severe obesity should be used to define maintained weight loss. This study found that this is not a suitable definition. Consideration should be given to future research seeking individuals who have ‘intentionally achieved their goal weight; sustained for at least one year’. 
Childhood experiences were a prevalent antecedent of obesity reported by the majority of participants, whether this was due to behavioural or emotional conditioning. This was supported by previous research where individuals experiencing poor attachment or a traumatic childhood use food as a way of regulating emotions (Hughes, Power, Fisher, Mueller & Nicklas, 2005; Larsen & Diener, 1987; Mazeschi et al, 2014). This highlighted the necessity to be aware of individual differences in history taking for clinicians and an understanding of the meaning that food had for each individual. Individuals may not be aware of how they began their relationship with food and as adults may not fully understand their use of food. Adults were found to be aware that they were overeating but were not aware of the reasons why. Avoidance of difficult emotions was a significant factor in this study, it revealed the difference between those who had maintained weight loss and those who had achieved 10% weight loss but were still fluctuating. Individuals with severe obesity were found to have difficulty experiencing negative affect compared to those who had achieved maintained weight loss and were using cognitive reappraisal for difficult situations in their life in addition to using expression of affect in reflective process (Moore et al., 2008). The latter interventions allowed the participant to gain self-awareness. The need for affect regulation in the treatment of individuals with severe obesity has been recognised (Abilés et al., 2010; Buckroyd & Rother, 2007; Zijlstra et al., 2012) and is a significant barrier to achieving maintained weight loss.

It was possible to identify negative cyclical patterns of behaviour around food. Food was used as a distraction from feeling a failure in life or a wish to escape from the person they had become. Food itself then becomes the object of their failure often following attendance at weight management programmes where they were unable to achieve weight loss maintenance. The individual then gets caught up in a vicious cycle negotiating self-blame, failure, shame and distress (Heatherton & Baumeister 1991; Klein, 2004; Owen-Smith et al, 2014; Throsby, 2007). Consideration needs to be given to recognising the implications of referring individuals with obesity and severe obesity to weight management programmes that alter and restrict diet without consideration to the individual’s psychological relationship with food and their affect regulation and self-esteem. Successful maintenance of weight loss for these participants was established through greater psychological awareness and self-acceptance in an environment that provided constant support and encouraged autonomy and responsibility. The importance of a form of constant support has been essential for the participants in this study and other studies (Gupta, 2014; Jensen et al, 2014). Ensuring adequate support both during and following an intervention programme is a significant gap in treatment. Participants were able to benefit from continued community support from like-minded individuals who had succeeded in achieving maintained weight loss and knew from their own experience the type of support required.

Whilst other studies have shown how affect dysregulation is associated with severe obesity (Berg et al, 2015; Haedt-Matt & Keel, 2011; Zijlstra et al, 2012) none have used an ideographic approach with individuals who have achieved maintained weight loss from being severely obese or produced a grounded theory to maintained weight loss. The inclusion of male participants has been limited in previous studies this is felt to be due to affect regulation only been seen as a female requirement. This study has shown that men benefit from greater psychological awareness and particularly self-acceptance. Limitations of this study focused on whether the level of saturation of the data with relevance to theoretical concepts was
achieved due to the limited number of participants found who met the revised inclusion criteria. Saturation of the data was achieved in terms of repeated constructs being observed. It is recommended that future studies obtain participants of both sexes who meet the amended criteria; this may ensure that saturation of theoretical concepts is achieved. Future prospective studies into the aetiology of severe obesity could focus on the childhood relationship between the participant and main caregiver, with particular reference to their attachment style and the use of food in this relationship. Research could also extend to the adult and their psychological relationship with food. This is an area that has been researched in obese individuals but greater insight would be beneficial for severely obese individuals.

The overarching findings obtained from this research with regard to facilitating maintained weight loss converge towards the core category of the ‘Emergent Self’. Recognising that by addressing the individual’s underlying psychology behind their disordered eating facilitates change for greater self-awareness and greater self-acceptance.

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**Commentary**

**The emergent self: a grounded theory of weight loss maintenance**

Anita Z Goldschmied, Managing Editor

If you are one of those few people who feels maintaining a healthy weight is a constant battle, then Carol, Wendy and Magi article can be a constructive read that summarises various theories of both obesity and the difficulties of maintaining our weight. Their paper gives due consideration to the complex issue of humans’ relationship with food. They discuss, how we are never in full control, and as life in the forest, the capacity to maintain a healthy weight is an effect of the myriad interactions between networks of elements that compose them such as childhood experiences. Yet, they suggest, the concept of “Emergent Self”, a psychological self-awareness of why and how we respond to those capacities and the potential effects might be a way to achieve success and a sense of control. Maintaining weight is a life-long task, not a one-off, and the paper concludes this. However, the beauty of complex ecosystems is that they remind us, there might be no one model that fits for all, and the same person might benefit from varied approaches at a different phase of their journey.
Experiences of Prader–Willi syndrome: a narrative account.

Abstract

This paper is a narrative account of a life experience of managing Prader–Willi syndrome (PWS). This research takes the form of a singular case study, using interview to highlight what life may be like for an individual with PWS, taking the perspective of a mother of an adult. The singular case study approach is justified due to the unique and original insight it brings; the singular, specific offering illumination upon general.

Issues of living with PWS – the management of food, desiring to excessively eat, not knowing the importance of maintaining personal hygiene and not being able to be gainfully employed are pertinent issues facing those with PWS. Finally, in the wake of this, this paper notes how some of these issues may be addressed and offers suggestions for those with PWS, their carers and practitioners.

Key words: Prader–Willi syndrome, narrative, qualitative, health and wellbeing.

Introduction and context

This paper presents a narrative life account based on an interview with a mother whose daughter has Prader–Willi syndrome. In so doing it offers an original insightful account of Prader–Willi syndrome (PWS). This work explored themes and detailed issues related to the difficulties associated with personal care, relationships and eating habits. The research concerns Bridget (pseudonym), who is 35, lives with her father (George) who has type one diabetes and looks after him, acting as a carer. This research uses an extended interview for data collection - interviewing Bridget’s mother (Sarah), who lives separately from Bridget and George. Bridget has Prader–Willi syndrome (PWS) - a rare genetic disorder due to loss of function of chromosome 15, inherited from her father (Waters, 2004). PWS is a complex neurodevelopmental disorder. Individuals with PWS have their own specific strengths and weaknesses but all tend to have a propensity to particular physical and mental health difficulties (Whittington, 2011). The condition causes continual hunger, excessive appetite and behavioural difficulties. Hence, if the individual consumes excess calories then they are more likely to suffer with weight gain and subsequent obesity problems. This could increase the likelihood of developing heart disease alongside respiratory problems, as well as type two diabetes, which could be fatal. (Hernandez-Storr, 2016).

Methodology

This research used ‘storying’ (Lewis, 2011) to gather qualitative thick description to describe a perception of the experiences associated with Prader–Willi syndrome (PWS). Moreover, Lewis (2011:505) notes, story is a ‘principal way of understanding the lived world.’ By encouraging personal narratives, specific life-transforming events can be shared, which offer enlightenment and some generalisability to other situations...
The use of singular case study was selected due to the in-depth account and the power of the life story narrative within an organisation and set of relationships (Yin, 2013). In so doing, this research asked Sarah to describe her experiences with a reflective notion of the holistic impact this had upon her and Bridget.

Although the single case study has to be handled with caution due to reliability issues (Cohen et al, 2017), tentative generalisability can be applied to which Interpretive Phenomenological Analysis (IPA) has been employed. This approach seeks to evaluate phenomenological description to the perceptive explication of the interviewee’s sentiments. By encouraging personal narratives, specific life-transforming events can be shared. The use of IPA is to allow for the emersion of rich data to shape the analyses of the work of small-selected samples, such as those interviewed. Smith (2009) notes phenomenology’s philosophical, interpretive approach begins with the individual seeking to attach meaning to life experiences without pre-conceived theoretical notions. The interviewers then elicited strands of meaning from the participants’ account; as an idiographic examination of each point was made to create wider deductions – follow up non-structured questions were used to check understanding - IPA acknowledges the role of the researcher in the process, whilst still employing interpretive analysis to subjective experiential data (Duncan et al., 2001). Moreover, the researcher was not removed from the context of the data collection procedure so the potential impact of the inter-subjective dynamics occurring between participant, data and analysis process must be noted (Finlay and Gough, 2003). Consequently, the researchers sought to use Erben’s schema of using imagination in the interpretation of the data sets, whilst being mindful of the overarching contextual dynamics, such as societal, educational and cultural factors, occurring within the participants’ life story (Erben, 1998). The potential impact of power-relations on participant responses during data collection was minimised by reiterating the sincerity of the researcher in listening and respecting the participant’s experiences and emphasising a feeling of equality between researcher and participant. In addition, it was important to emphasise that no judgements were being made, especially with the sensitive nature of the matters raised. The researchers suggested that this may offer potential empowerment to share life accounts which may inspire or help other people.

Research aims

Data from the interview, of which the salient points were transcribed, coded and thematically analysed. In narrative analysis participants re-tell life experiences, seeking to attach meaning to specific events of significance. Judicial caution was applied noting the subjectivity of what was said as much ‘memory work’ was involved, which needs to be situated within a context (Willig and Stainton-Rogers, 2017), hence the use of IPA. The interview guide was framed around a set of themed ideas which developed into questions, an approach of Roller and Lavrakas (2015). Sarah was asked to describe her experiences of managing Bridget’s PWS in the past, but more, at present (being the foci of the study). The key questions explored were:

- How does Prader-Willi syndrome (PWS) impact upon a life?
- How would you describe your experiences of caring for Bridget as a girl and as a woman?
- What approaches did or do you take with Bridget?
- What do you see the long-term picture looking like?
Research Data

The demands of PWS were highlighted in the pertinent points transcribed and thematically analysed using IPA in the section below, applying the ‘bottom up’ approach, generating codes from the data.

Sarah said that Bridget, due to the condition of PWS, would have a high metabolism, keep eating and have no concept of when she was full. Therefore, she would ‘continuously look for food’. As a young girl locks would have to be put upon the cupboard doors to ensure she did not snack between meals or when nobody was around: ‘Bridget would have to have locks on the cupboards downstairs in case she got up in the night and ate things in the cupboard.’

As she had no concept of when she was full, she would eat all the time, put on weight and had recently become in the region of 26 to 30 stone. Sarah reported that Bridget had difficulty managing personal hygiene due to carrying excessive fat and attended social gatherings, church services and other events smelling of body odour This causes people to avoid her due to the magnitude of the unpleasant odour and she consequently becomes even further isolated. Sarah noted how if ever she was invited around for coffee or Bible study after church a special individual study for her as some people refused or had been put off from coming by her smells, all the house would smell stale and odorous. She would put a rug over the sofa to stop the smell seeping through and would detox all the surfaces after she had been. Whatever the weather, Sarah would be forced to leave the door open for around half an hour after she went to prevent the smell lingering.

Sarah additionally recounted how the suspension of her car was affected after several occasions in which she gave Bridget lifts to and from her house to church, hospital or work: ‘The garage said that there was something not right with the suspension and I know it was after taking Bridget’. On some occasions she had broken furniture in the church, at home or in public. Bridget at times got sensitive when things like this occurred. However, when the subject of weight management and looking after yourself was raised she would ‘zone out and not listen’. On occasions she had been with a friend to weight watchers but had not sustained enthusiasm for any period of time or committed herself to losing a significant amount of weight with help and support.

Bridget does not currently work and has a low intellect / IQ. She had begun a floristry course at a local college but had terminated it due to the assignments, which she found unmanageable. With her weight problem she finds certain jobs challenging. Working in a supermarket, for example, would be difficult because cravings for food would arise from scanning edible items at a checkout. She also would find some jobs difficult to do such as working in a supermarket, scanning items of food on the checkout due to the feelings of cravings for food. This, Sarah suggested, would be ‘cruel as she would always be seeing lots of items of food pass her by.’ However, she would also find corner shop work difficult due to the physical space she would need to work in; taking up more space than a single person behind the counter.

Sarah did not know what the future would hold for Bridget. Lots of employment avenues seemed to be shut for her as her IQ was low and she would have mood issues, affecting social relationships. Spending long periods of time at home was not deemed by Sarah to be helpful for Bridget; Sarah recommended that having a goal in life would benefit Bridget. Her father had prompted her to put her name down on the council list for houses so that
when he died she would have somewhere to live. He had also encouraged her to take some exercise and she held a step-count monitor which she sought to increase each week. In relation to the long-term picture, Sarah was quite upset to try and picture what would become of Bridget in the future; ‘I don’t really know what will become of Bridget, it’s so hard to think of what she can do or will do.’

Discussion

As collated from the participant’s responses. The main problem identified by Sarah related to Bridget’s excessive appetite which consequently led to:

- Weight gain
- Obesity and associated health problems
- Issues with bathing / personal hygiene
- Problems with employment (also impact of low IQ)

Each will be considered in turn:

Weight gain caused by over-eating is a significant cause of heart disease and mortality (Caldwell and Taylor, 2013). Moreover, PWS is associated with relentless weight gain in adults with untreated PRS (Holm et al., 1981:273). Consequently, regular exercise and management of diet are key features emerging from this narrative, which need to be addressed to help support Bridget.

Butler et al. (2006:415) notes:

The basic premise of intervention acknowledges that at no time can a person with Prader-Willi syndrome be expected to voluntarily or independently control his / her food consumption. ... an exercise program, activities of daily living, chores, and personal hygiene are all supported by the therapeutic milieu.

Therefore, controls on diet, such as training on how to cook meals from raw ingredients (if capable) or purchase ready meals which are nutritious and healthy are important in helping an individual with PWS. The above sentiments of Butler et al (2006) suggests that someone with PWS will never be able to be completely independent? Will they require a carer to visit them? Perhaps training in buying healthy ready meals will only benefit people with this condition so far? As unchecked, individuals may consume excess calories of foods which provide little nutritional value and compound weight gain. For Bridget, as a young person, having locks on cupboards meant that, although it may appear oppressive, she did not over eat after mealtimes. As Sarah said ‘she could put five stone on in a year otherwise.’ However, the locks of cabinets appeared only a short-term solution, a long-term approach designed to help manage compulsiveness or hunger suppression tablets or hormonal / thyroid medication is potentially required.

Obesity and the interconnectedness of other health issues are key features of PWS (Eiholzer, 2001). Therefore, ensuring rigorous but empowering actions to monitor the types of food eaten on a chart could provide a useful tool to monitor consumption. Being open at health care sessions with practitioners and being held to account with others such as at Weight Watchers is potentially a good way of learning the importance of how many calories are in different foods and ensuring weight is managed and reduced over time. Sarah noted now she did not even expect to see Bridget alive after 30 years old because in the last few years she had fluctuated in weight and most recently put on several stone in a matter of months. This was, in Sarah’s view, due to the lack of accountability Bridget felt she had towards her father and mother now as an adult. Sarah makes the case for intervention for this eating problem happening.
much earlier on so that she has the opportunity to train herself into good habits from an earlier age.

Issues with personal hygiene can be associated with the condition and therefore managing practical issues into a step-by-step approach helps; dressing, personal care and so forth (Waters, 2004). It is clear that a key feature emerging from this narrative is the smell that Bridget makes when she does not adhere to matters of personal hygiene attendance. A rigorous approach to emphasising the importance of washing thoroughly and of smelling fresh appears to be needed as potentially this may not be fully understood by Bridget due to a low IQ. This is also impacted by inability to reach certain areas of her body due to excess fat/skin folds, that these habits need to be developed early on because, despite low IQ, the mind might be trained for long-term coping mechanisms.

Problems getting and maintaining a job are key features of the sentiments of Sarah. ‘The employment scripts of knowing and following the “rules” of a job setting and knowing and using the “politics” of a job...’ (Reynolds and Fletcher-Janzen, 2007: 1611) are difficult to grasp for those with PWS in a competitive market for employment. However, jobs which combine both exercise and routine and do not require analytical deductions, working out change or problem solving are likely to be suitable for Bridget. Supported employment opportunities can help individuals with PWS (Goldstein and Reynolds, 2005). Moreover, Butler et al. (2006) suggest cleaning, lawn mowing and restaurant work as potential jobs for those with PWS. These types of jobs, and others such as: warehouse work, gardening, shop assistant, would allow Bridget to move and therefore, get exercise and feel a sense of purpose. I would caution the sentiments of Butler et al. (2006), suggesting the restaurant job may be detrimental to health, due to the contact she would have with food, potentially making her desireous to excessively eat) here, seeing as restaurant work would challenge the very nature of the difficulties that the condition brings.

Conclusion

PWS impacts upon the life choices and trajectory of those with the condition and those associated with looking out for them. In this narrative account it is unclear what will happen to Bridget in the future, particularly when the support of her parents is no longer available. James (2010) reports on a Canadian approach to PWS for middle-aged persons in which their dreams and ambitions are recognised and supported. Additionally, accommodation with nearby call-staff is another effective idea in supporting individuals with PWS. The tenets of this approach is recognition of need whilst at the same time noting that developmental disabilities and genetic differences should not ostracise the individual from the wider world.

It is important from the discussion of the salient points raised through IPA that Bridget seeks help and is accepting of Sarah’s advice in the key matters of weight management and loss, personal hygiene and employment. However, it could be questioned: is she accepting of advice? Is the problem more that she zones out? This work underlines the importance of listening to unique perspectives of what life is like for those with PWS and of those around them. This research is of importance because it highlights a rare condition and provides a first-hand account of the problems faced on a daily basis, which adds to the minimal existing literature on individuals affected by this condition. Additionally, it accentuates the wider problem of lack of management for the condition, which sees lack of training for individuals with PWS in their younger years consequently being unable or unwilling to seek the support they need.
to deal effectively with the issues that arise within their adult years.

This study is justified because it illuminates the problems faced by people with PWS and offers a powerful insight into the world of PWS. It further provides original insights with generalisability for others involved in the care and provision of those with the condition. It finally presents a call for more research in this area in relation to life-training skills to aid people’s management of the condition.

References


**Commentary**

**Experiences of Prader–Willi syndrome: a narrative account**

Anita Z Goldschmied, Managing Editor

Johnathan’s detailed narrative is an important reminder of using a methodology that keeps people and their experiences at the centre of inquiry. The link between the tendency of overeating and Prader-Willy Syndrome is a well-known and researched issue in the scientific arena. However, we often forget the personal, both in terms of living with or caring for someone with such a condition. Have you ever wondered whether there are overweight animals in the forest? Or whether animals overeat? The paper answers the question. They have no health and social care system in place to provide them with food once they are so overweight that cannot go and find food anymore. So, whilst they could and occasionally do overeat life in the forest ensures they will quickly become fit and lean compared to their own body and not to an artificially composed ideal for all. The paper highlights pressing issues around employment and health problems whilst offering some interventions that might seem restrictive at first. Yet, once we considered the benefits of living in the forest, we find that the locked cupboard is an ecosystem all of its own.
Exploring skill-mix to enhance community service delivery
Emma Dudzinski Lecturer in Occupational Therapy
School of Health Sciences, University of East Anglia,
Norwich Research Park, Norwich, NR4 7TJ

Introduction

Older people are the main users of health and social care services in Great Britain (Department of Health [DH], 2001; Howse, 2007). The number of older people in the UK is increasing and projected to increase to almost a quarter of the population by 2045 (Office for National Statistics, 2017). This will place further pressures on health and social care services at a time of increasingly scarce resources; and requires local authorities to consider new and innovative ways of working to meet these needs. Thus there is a responsibility for occupational therapy to demonstrate the effectiveness of its services for older people in social care settings.

Many older people have long term conditions that result in limitations in physical activity and function (Melis et al, 2008). Maintaining functional ability is important, not only to enable a person to carry out independent activities of daily living, but to also reduce caregiver burden and influence the wellbeing of both (Peters et al, 2013). Difficulties performing activities of daily living such as bathing or mobilising at home represent significant events that may trigger the need for personal assistance or relocation to a family member’s home or residential facility (Gill et al, 2006). Moreover, functional difficulties are associated with a reduced quality of life, fear of falling, functional decline and depression (Spillman, 2004; Feng et al 2014).

Glendinning et al (2008) highlighted that interventions with a focus on activity, independence and successful ageing are more effective than those based on a dependency service provision model. This is supported by the Adult Social Care Outcomes Framework 2013/14 (DH 2012) which focuses on delaying and reducing the need for care and support. The Care Act (2014) placed a responsibility on local authorities to provide preventative services to defer the need for expensive, institutionally based, interventions in times of crisis. The Royal College of Occupational Therapists (RCOT) (2017) demonstrated how involving the older person in decision making, seeing the whole person, and focusing on what they can do, results in a better quality of life for the older person, reducing their need for long term care.

Occupational therapists play a fundamental role in promoting function and independence by removing barriers, adapting or modifying physical environments and offering support, guidance and education for individuals and caregivers. This paper offers two case study examples of an innovative service, in a local authority in England, combining the expertise of both occupational therapists and assistant practitioners. All names are replaced with pseudonyms to preserve the anonymity of participants.

Motivations for a new approach to service delivery in Adult Social Care

The motivations for a new service delivery model came from increased pressures on the locality’s
social work waiting list whilst there was capacity in the occupational therapy and assistant practitioner assessment service. In line with the Care Act (2014) prevention principles, we looked for service improvement which would embed a culture of promoting independence for clients whilst motivating the team by generating innovative ways of working. Furthermore, we hoped to contribute to budget savings by reducing commitments to long term packages of care whilst managing expectations and perceptions of the social care remit by the public.

Methods

Project Model

Combining the concepts of ‘occupational therapy first’, ‘strengths based assessment’ and ‘promoting independence and prevention’, we nominated two pairs of occupational therapists and assistant practitioners to focus on new referrals coming into the department, requesting a package of care, where there were no existing services. These cases would have normally been assessed by a social worker.

We aimed to utilise the occupational therapy functional assessment, creative use of resources, a strengths based approach focusing on the person’s own capabilities and wider support network, and knowledge of local voluntary, third sector and community resources to prevent, reduce or delay the need for funded care. We used the occupational therapy and assistant practitioner skill mix to combine the holistic functional assessment skills of an occupational therapist with the support planning skills and community based knowledge of an assistant practitioner. The occupational therapist would also lead any complex issues or mental capacity assessments. The visits were joint, both practitioners contributing to one assessment avoiding duplication in recording, with the expectation that there would be little or no reduction in the numbers of cases seen.

Ethical approval was not necessary as this was audit and service evaluation. The activity was usual service improvement hence explicit informed consent was not required.

Findings

Case Study: John

John is diagnosed with Alzheimer’s disease and arthritis affecting his back. He lives with his wife, Mary, his main carer. John was referred to Adult Social Care requesting support with bathing, after becoming stuck in the bath.

Assessment

The Occupational Therapy and Assistant Practitioner (OTAP) assessment took place at John’s home with his wife and son present. This was a familiar environment for John and enabled functional abilities to be observed within his home setting.

The assessment used a holistic biopsychosocial approach focusing initially on the reason for referral (bathing difficulties), but also exploring the impact of John’s long-term conditions on other aspects of his daily living routine using discussion and observation. Having two practitioners present enabled the occupational therapist to spend time alone with John observing his mobility and transfer technique, whilst the assistant practitioner completed a carer’s assessment with Mary, assessing her needs and the impact of her caring role. Littlechild et al (2010) identified that assisting family carers was one of three main important features for promoting or maintaining service user independence.
John had reduced balance but was mobile with a walking stick. He had difficulties with bath and toilet transfers and experienced balance problems on the stairs and when transferring in and out of the property. Mary reported that John became disorientated at night in the dark, and could be verbally aggressive.

**Intervention**
The occupational therapist ordered a bath lift, additional banister rail and two toilet frames to increase independence and safety at home. Following the prevention principles of the Care Act (2014), information and advice was provided for the family to explore grab rails and a half step at the front access. This promoted wellbeing by increasing the ability to exercise choice and control and is a vital component to prevent or delay a person’s need for care and support (DH, 2017). Mary was regularly travelling by taxi to collect John’s medication which was time consuming and expensive, the assistant practitioner suggested exploring a medication delivery service. Mary asked for support managing her husband’s verbally aggressive behaviour and support from the Mental Health team was advised and information regarding the Alzheimer’s Society provided. Cohen-Mansfield (2001) suggest people with dementia behave in an agitated manner when their needs (for example for social interaction) are not correctly perceived and addressed by caregivers. The assistant practitioner suggested referral for a volunteer to provide John with some social stimulation and providing Mary with a break from her caring role. A referral to Assistive Technology was made for motion sensor lights, and a sensor to alert Mary when her husband gets out of bed, to address disorientation at night time.

**Outcomes**
John and Mary felt the provision of equipment made a positive difference to John’s independence and safety reducing his likelihood of falls on the stairs. Mary also reported that John needed less support to complete activities of daily living with the equipment in place, as found by Sainty et al (2009) who showed equipment provision made people feel safer and more independent, reducing the need for support. Here, provision of equipment, onward referrals and information and advice prevented the need for funded care and the joint OTAP approach enabled a carer assessment and occupational therapy assessment to be completed within the same appointment. This reduced visits and waiting times, enabling a holistic and empowering process for both service user and caregiver.

**Case Study: Sarah**
Sarah had a stroke one year ago resulting in language, comprehension and expression difficulties. She can only read and write a few words and experiences difficulties with managing her correspondence. Sarah lives alone, with no family or friends able to support this task. Her speech and language therapist requested a social care assessment, for a personal budget, to enable Sarah to employ a personal assistant to support her with correspondence.

**Assessment**
The OTAP assessment took place at Sarah’s home with her speech and language therapist present supporting communication. The occupational therapist and assistant practitioner used gestures and short phrases when communicating with Sarah, giving her additional time to respond, to help improve her participation in the assessment.
Questions were addressed directly to Sarah, using the speech and language therapist only when necessary, ensuring a person-centred approach (Morris et al, 2015).

In the assessment, Sarah demonstrated difficulties accessing her over bath shower, right sided weakness and reduced sensation, in addition to expressive and receptive aphasia.

**Intervention**

The assistant practitioner requested a long-term volunteer to support Sarah with managing her correspondence and explored local support groups that she might attend. This is supported by Ch’ng et al (2008) who suggest engagement in new activities and social support appear to be key factors in post-stroke adjustment. More time in the home is experienced by people as they age, however, accessing the community and being involved in social activities remains essential for health and wellbeing (DH, 2014).

The occupational therapist trialled bathing equipment to assist Sarah to access her over bath shower; however, this remained difficult and the shower was not temperature controlled. A thermostatically controlled level access shower was recommended via a Disabled Facilities Grant (DFG), to enable safe and independent access to bathing facilities.

**Outcomes**

The volunteer provided long term support with correspondence preventing the need for funded care. A level access shower with shower chair was installed enabling independence with bathing, this was an additional need, not highlighted in the initial referral. As Gill et al (2006) note, it is important to restore and maintain independent bathing for older adults, to prevent further deterioration in functional ability. The joint OTAP approach enabled eligibility for the DFG to be identified early which would not have otherwise happened as the referral was for a social work care assessment, not occupational therapy. If the social worker had identified the need for an occupational therapy assessment, further delays would have occurred due to the waiting list. Powell et al (2017) found delays in referrals for adaptations mean that help may come too late to maintain independence. Timely housing adaptations consequently have scope to promote autonomy and reduce demands on families and formal services (Allen and Glasby, 2013). There is potential here for significant cost savings and improved preventative outcomes for service users and caregivers.

**Discussion**

Wellbeing is recognised as important in the Care Act (2014), it is vital that local authorities refocus, creating social care services that help older people to do as much as they can for themselves, for as long as they can. To meet the challenges of the future, services must intervene early, help people retain or regain their skills, and prevent or delay deterioration wherever possible. This may mean a period of intense support or home adaptation, however once goals are achieved, support may be safely reduced or even withdrawn.

The joint OTAP service delivery model meets needs through low level equipment, information and advice, education, voluntary and third sector interventions, signposting, DFG adaptations, carer’s assessments and short-term interventions from reablement services. Anecdotal feedback from service users suggests moving away from a dependency service provision model is ‘enabling’ and ‘giving control back’.

Practitioners felt positive and motivated by the model, and reflected on the development of their
skills. Assistant practitioners reported observing the service user in their own environment, led to an evidence-based understanding of risk, and increased knowledge on how to meet needs without a care package not revealed by a static talking and listening approach to assessment. Occupational therapists reported feeling they worked more proactively and were able to apply clinical reasoning in practice at the time, rather than reflecting back on practice after the visit. Workers felt key factors for success were the strong joint working partnership and seeing service users in their own environment.

As the majority of cases seen were those with no current services, it is difficult to accurately reflect the savings achieved. A visit from two practitioners may be perceived as an expensive approach, however analysing the referrals and estimating a predicted spend based on that information and average costs of care, showed a predicted saving. Over six months 84% of cases seen using the OTAP approach were met without funded care or resulted in a reduction of care. No second assessments were needed and the length of visits was no greater than a single practitioner case. The organisation predicted an annual saving of one million pounds by using this approach, suggesting that finding innovative ways to enable people to continue to participate in daily life can provide more effective use of public money.

Most cases seen, using the OTAP approach, were referred for social work intervention, but have benefited from equipment, adaptations and focused advice around managing conditions and daily routines. This joint approach is predicted to reduce the number of internal referrals to occupational therapy from social workers and assistant practitioners, potentially preventing the need for a second assessment, and the need for the person to repeat their story.

The RCOT (2017) recommends that occupational therapists are employed to develop person and community-centred approaches, ensuring older people live independently for as long as possible in their communities. This report also suggests service design should allow occupational therapists to adopt a more preventive and enabling approach. The joint OTAP model exemplifies these recommendations by promoting a holistic and strengths based intervention.

**Conclusion**

This service evaluation outlines two examples of using the OTAP approach within an Adult Social Care setting. The implications for practice are the opportunity to reframe how we approach assessing and provide for people with care and support needs. Taking a preventative approach; giving information and advice, developing resources and working with communities, occupational therapists and assistant practitioners have worked collaboratively to prevent, reduce and delay the need for funded care. This led to significant predicted savings and maintenance of independence and wellbeing for service users.

Anecdotal feedback suggests this is an empowering approach for service users which motivates practitioners and expands their knowledge. Eligibility for DFGs was identified in a timely way, with reduced internal referrals to occupational therapy. Availability of this service has been increased with plans to implement this approach across other localities.
References


Commentary

Exploring skill-mix to enhance community service delivery
Anita Z Goldschmied, Managing Editor

Emma’s article and the case studies remind us that providing older adults with health and social care interventions in the 21st Century is like navigating a forest and finding our way out but doing it in a way that also enhances the ecosystem. And this is not a small task when we consider the complex interacting organisms and the physical environment. Can one professional have all the skills to assess, plan and provide interventions in such a complex network? Well, the Care Act (2014) places a statutory duty on local authorities to promote independence and reduce dependency on care and support provision. The article offers a service delivery model that utilises skill-mix to optimise care both in terms of efficiency and effectiveness. It invites us to reflect on how we draw the boundaries between disciplines. What skills should professionals possess? Could any other professionals be involved? How have they ensured no duplications are recorded? And if they have different tasks to perform then what are the actuals benefits of carrying out an assessment in one time rather than through two separate visits? Probably further investigations and pilots could explore such details.