**Meeting Report:**

**Adherence to Treatment Recommendations in Chronic Disease: What is (im)Possible?**

**Expert conclusions from the 30th ECOG workshop 2021**

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Short Title: Adherence to treatment in childhood obesity

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**Adherence to Treatment Recommendations in Chronic Disease: What is (im)Possible?**

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**Abstract**

Obesity is a chronic disease, in which treatment outcomes are highly dependent on patient and family adherence to behavioural recommendations. The role of healthy eating, physical activity, medication adherence as well as adherence to pre- and post-bariatric surgery protocols are of utmost importance for long-term treatment outcomes. Even the best interventions are not likely to reach their maximum benefit without significant levels of adherence on the part of the individual and family. Traditionally, the annual meeting of the European **Childhood Obesity Group (ECOG)** includes an expert workshop addressing one specific topic within the field of childhood obesity. During the 30th annual meeting, hosted by the University of Pécs, Hungary, as a virtual meeting, “adherence to treatment recommendations in obesity as a chronic disease” was addressed. The discussions that developed during the workshop are summarized in the following article.

**Introduction**

The**European Childhood Obesity Group (ECOG)** is a pan-European group of professionals dealing with childhood obesity and overweight.  ECOG was founded to gather and support healthcare providers in delivering evidence-based assessment and treatment of childhood obesity. Traditionally, the annual meeting includes an expert workshop addressing one specific topic within the field of childhood obesity. During the 30th annual meeting, hosted by the University of Pécs, Hungary, as a virtual meeting, “adherence to treatment recommendations in obesity as a chronic disease” was addressed. The discussions that developed during the workshop clearly highlighted the major concerns faced by clinicians and practitioners and are summarized in the following article.

Obesity is a chronic disease [1] [2], in which treatment outcomes are highly dependent on patient, parent and family adherence to behavioural recommendations [3][4][5]. The role of healthy eating, physical ]be emphasized strongly enough [3] [5] [6] [7]. Even the best interventions are not likely to reach their maximum benefit without significant levels of adherence on the part of the individual and family [8].

Pediatric and adolescent obesity is a particularly important context in which to improve adherence due to the evidence that highlights neurobiological and hormonal responses to weight loss which serve to protect one’s highest weight [9][10][11]. That is, with the accumulation of adopsites there are neurohormonal changes (proinflammatory markers) that alter the appetite system in favour of overconsumption and alter the response to weight loss to favour regain. Interrupting the trajectory of overweight and obesity from early childhood to adulthood [12][13] by intervening in the pediatric context may be the most effective strategy in obesity treatment

By classifying obesity as a chronic medical condition [14], it is expected that the appropriate treatment model from which to organize care is the Chronic Care Model [15]. This model is distinguished by its acceptance of the complexity of the condition and its management, by the central role of engaging the person and family in their care, and by the need for ongoing support.

Adherence to recommendations for management is a critical issue in the development of effective intervention plans to treat obesity [16]. Evidence suggests that adherence is problematic in obesity lifestyle intervention trials, where previous trials have shown that as many as 80% of participants drop out of trials [3] [17]. Further, medication nonadherence is very common, where estimates suggest that as many as 30% of individuals do not fill an initial prescription [18], and as many as 60% of those with chronic illnesses do not persist with medical therapies beyond two years [19]. Behavioural epidemiological studies go one step further and suggest that basic healthy lifestyle behaviours such as healthy eating, physical activity, safe alcohol consumption, and adequate sleep are less rather than more common [20][21]. For children an adolescents, health literacy [22] as well as socioeconomic factors of parents [23]

If we accept that adherence to clinical recommendations in obesity treatment is an issue of concern the main question is: how do we get more out of the treatments we offer by increasing adherence? In this paper, we take an interpersonal perspective on the issue of adherence to recommendations. To offer a perspective from the outset, we suggest that when patients or parents/family members are not ready to follow recommendations it is the patient or parent-provider relationship that is essential in overcoming barriers to adherence. Without establishing a patient-provider relationship that supports change (from nonadherence to adherence) the patient would be left on their own to develop the motivation to change [24]. It is likely that if this motivation were to develop spontaneously it would be driven by a negative event (onset of illness; interference with function). What if the patient or parent-provider relationship were able to help move the person from being ambivalent or resistant to clinical recommendations to being accepting of, and motivated to follow through on, clinical recommendations?

There is great value in examining adherence from a relational perspective [25][26]. Considering clinicians, it is common for providers to adopt the role of being the expert, whose job it is to make a diagnosis and recommend an evidence-based treatment; once these tasks are completed the clinician’s job is done, save for measuring outcomes in follow up. From this perspective, encountering nonadherence could easily evoke frustration, which might impair patient or parent-provider trust [27]. Considering patients or parents/family, research has suggested that nondisclosure of relevant medical information is common, including disagreeing recommendations, not taking medications, and not understanding the clinician’s instructions, all without disclosing this to the healthcare provider [28]. Reasons for nondisclosure included not wanting to be judged or lectured by the clinician, not wanting to be embarrassed, or not wanting to be thought of as difficult. Imagine the challenge of a situation in which the clinician is frustrated and the patient or parent fears being judged. This is not a change-based relationship. Motivational communication strategies [27], such as motivational interviewing [29], come into play here nicely. Avoiding the dangers of a “teach and tell” perspective, normalizing that change is hard and establishing a patient or parent-provider relationship based on bond, task and goal alliance are key to a change-based relationship and a context from which to improve adherence [27].

Nowhere in chronic disease management is a change-based relationship more critical than with obesity management. This is because the typical person/family views obesity and its management from an unrealistic perspective. Specifically, the dominant narrative in the public eye is “I can reach my goal weight by eating less and moving more using willpower” [30]. Framing obesity management in the context of a relational dynamic (a change-based relationship) allows this false narrative to be exposed and reframed. One way of framing this is as follows: patients or parents have one overarching question when consider committing to an obesity management intervention and evidence-based management provides a disappointing answer. The question of the patient or parent almost invariably is, how much weight will I lose? And the evidence-based answer of the health-care professionals is, I do not know exactly how much weight you will lose, and I am more interested in your health gains that can be achieved by adhering to the recommended changes than in number of kilos lost. The discrepancy in goal setting is challenging indeed.

Supporting adherence in obesity management can be achieved by accepting this current tension between weight being a chronic disease (our perspective) and weight being under behavioural control (our patients’ or parents’ perspective). The patient or parent-provider relationship allows three important issues to be addressed that will directly impact adherence in a positive manner. These are: addressing the expectations that promote bias and stigma; supporting effective behaviour change that appreciates that change is not linear; and linking adherence to motivation through readiness.

Addressing Expectations That Promote Bias and Stigma

Perceiving weight as a behaviour can negatively impact adherence. If weight is a behaviour, it should be under behavioural control. The naive energy in - energy out perspective on weight loss has allowed individuals to approach weight as if it were like a gas pedal and speedometer; you control the speed. It encourages people to set weight loss goals as specific numbers on the scale. Almost everyone presenting for weight management has a specific number in their mind that they would like to reach. The reality that weight and the appetite system are driven more by biological factors interacting with environmental contexts driven than by desire and willpower has set people up for disappointment. Virtually all weight loss efforts, including bariatric surgery, demonstrate the classic weight loss curve. Early in the weight loss journey there is a nice effort-equals-outcome decrease in weight. This downward sloping curve inevitably ends in a plateau which is a biological imperative not, a behavioural failure. Yet for the person seeking weight loss this is perceived as a failure experience, which promotes internalized weight bias and learned helplessness, two very negative psychological states[31][32].

If we frame adherence in obesity management as relational, the clinician has the opportunity to use communication skills to help the patient or parent reframe obesity from the “achieve goal weight by eating less, moving more using willpower” to obesity as a chronic medical disease, in which weight is not a behaviour, weight loss is determined more by biological and environmental than behavioural factors (such as set point, or settling point theory, [33]) and success is measured by health, function and quality of life [30]. Nonadherence in obesity management can be related in part to the patient or parent experiencing disappointment about not achieving unrealistic expectations. Learned helplessness is created by a lack of connection between effort and outcome. Reframing expectations such that the patient or parent focused on goals that are achievable, such as walking half an hour 3 times a week, taste a new vegetable or fruit 3 times a week, lower cholesterol, or practicing stress management twice per week, can increase adherence. Motivational communication (Ask, Listen, Summarize, Invite/Inform [27]) using strategies such as the 5 As (Ask, Assess, Advise, Agree, Assist [26]) provides clinicians with guidance to support patients or parents to reframe their experience from negative (“no matter what I do I cannot lose all the weight I want”) to positive (“my efforts have improved my health, ability to function and self-esteem”) [34].

Adherence is not Linear

Human behaviour is influenced by two important drive systems [35][36]. Hedonic sources of behaviour are rooted in the limbic system and these drives are based on pleasure, ease, and immediate gratification. A second behavioural drive system is located in the frontal lobe and are referred to as the Executive system. This system is characterized by rationale thought, delay of gratification and distress tolerance. This system requires mental resources to function and is prone to fatigue. The Nobel prize winning Psychologist Daniel Kahneman has described this as fast (limbic) and slow (executive) thinking [37]. The work of Borland [38] should also be emphasized. The CEOS theory (Context, Executive, and Operational Systems) helps us differentiate between hard-to-resist behaviour (chocolate; limbically controlled) and hard-to-initiate/sustain behaviour (regular physical activity; frontal lobe controlled), and suggests that we need different treatment strategies for behaviours driven by the two systems. Of particular relevance to this paper, the executive functions are not fully developed until early adulthood.

Acceptance that behaviour is driven by both emotion and logic helps us to appreciate how normal ambivalence is. That is, a very common psychological state for a person to be in is one of conflict between what one feels like doing and what one thinks they should do. In addition, most of us now live in societies whereby the healthier option is harder to initiate and sustain than the less healthy option. Contemporary environments make access to calorie dense, nutrition poor, large quantity (supersized) food options, provide technological conveniences that do not require much physical exertion (travel by car, communicate by text, relax with screens), and are organized so that there is little time and/or money to attend to nutrition or activity [39][40]. Therefore, effective health-promoting strategies driven by the policy, such as introducing front-of-pack labels (e.g., Nutri-Score) [41], or economic tools, such as introducing price increasing for sugar-sweetened beverages [42], are needed to further support the self-management of children, adolescents and adults.

Adherence can be viewed as persistence of a behaviour over time. It is a special type of persistence however in that adherence is persistence with the behaviour recommended by the clinician, not chosen by the patient or parent. Given how behaviour is guided by internal factors (the struggle between emotion and logic) as well as external factors, such as social support, social determinants of health and the powerful media, one might expect change to be hard and setbacks to be common. If so, reframing adherence to a relational construct between the provider and the patient or parent, a pathway to success in promoting adherence can be described.

Adherence can be promoted if the provider, based on establishing a change-based relationship, were to ask permission to educate the patient or parent about the challenges with behaviour change (normalizing that change is hard) and collaborate to identify the specific factors associated with nonadherence [34][27]. As such, nonadherence is not framed as a problem (as in failure, or setback) but as an opportunity for learning. Episodes of nonadherence provide a rich context to understanding the person-centered barriers to change (reasons not to change). Welcoming the reasons not to change as part of behavioural interventions provides the opportunity to consider strategies (behavioural, interpersonal, cognitive strategies) to overcome these barriers. Further, Health care providers can use the relationship to collaborate with the patient to agree upon the type of rewards that can promote habit formation.

Linking Adherence to Readiness

A successful journey in obesity management would involve reframing one’s expectations that weight is entirely under behavioural control to success is measured by health, function and quality of life [43]. This would be followed by motivational and behaviour change strategies to make the healthier choice easier, due to habit formation, environmental shaping and values-based actions. Together this would result in the patient or parent committing to behaviours that can be sustained because they represent success not failure (reinforcement not punishment). Adherence would be supported by clinicians collaborating to help patients or parents appreciate the barriers to change and develop strategies to overcome these barriers. This leads to an important psychological state termed self-efficacy; confidence to overcome barriers [44]. The final step to success relates to intrinsic motivation; that is, the development of personal, meaningful reasons to accomplishing the behaviour despite barriers. This state reflects that the behaviour in question does not require external motivation but is internally driven. Again, in this paper we take the position that the relationship between patient or parent and provider can guide this process.

Readiness to change is an interesting construct in that it incorporates several important aspects. First, the behaviour in question is currently not being performed; one cannot be ready to change if they are already doing that behaviour. For instance, it makes no sense to assess the readiness for nonsmokers to not smoke. Second, given that change is hard, the person must have reasons to change. This is often appreciated when one examines the person’s attitudes and feelings. Readiness to change can be seen as based on a judgment that not engaging in the behaviour is problematic for the person (someone who rationalizes their behaviour – I used to smoke 30 cigarettes I now only smoke 20). Further, not changing is likely to be a source of emotional distress (if I am not bothered by smoking 20 cigarettes per day why would I change). Third, the person must have a goal to change their behaviour that includes the tasks associated with achieving that goal (wanting to increase fitness is not the same as wanting to get up early to add exercise to one’s day). Finally, readiness would imply that the person is willing to commit to the behaviour in the immediate timeframe [27].

The concept of readiness is also helpful because it provides a context for the person to not be ready. Research based on the Transtheoretical Model of Change (stages of change) was very helpful in identifying that for a great number of health behaviours the majority of people were not in action stages [45]. Recent work has involved a semi-structured interview that asks about behaviour change through the lens of understanding if behaviour is considered a problem, a source of distress, if the goal is to change behaviour, and if the person is ready to change now. This assessment is an interview in which the results are understood using a traffic light metaphor; green light for ready, yellow light for ambivalence and red light for not ready.

The provider can support adherence by helping the patient or parent to appreciate their readiness to change. Motivational communication and shared decision making allow the patient or parent and provider to work together in follow up to set appropriate expectations, to identify and work to overcome barriers and the use the transactional readiness concept to invite the person to work together to increase readiness to change (i.e., work with people to address issues associated with being not ready or ambivalent about change). One of the most beneficial aspects of this readiness concept is in working with families. It is very common for different members of a family to be in different states of readiness with regard to behaviour change. Labelling readiness in a nonjudgmental manner allows collaboration and an invitation to work together to overcome barriers to sustained change.

Conclusion

Treating obesity in children and adolescents is perhaps the most important aspect of bariatric medicine. Interupting the weight gain trajectory that applies to most of the countries of the world will prevent untold human, social and economic costs. As we see increased attention being paid to the importance of defining obesity as a medical disorder and developing behavioural, medical and surgical treatments there is clearly reasons for optimism. However, this optimism may be tempered by the fact that the pathway to success in obesity management requires adherence to treatment recommendations. In this paper, we have taken an interpersonal perspective on the healthcare provider – patient relationship to describe strategies to improve adherence. These strategies are rooted in evidence based treatment, the patient-centered method [46], and shared decision making. Specifically, it is proposed that adherence to obesity treatment recommendations can be enhanced by using the healthcare provider-patient relationship to reframe expectations of weight loss in a manner than reduces bias, stigma (including self-stigma) and learned helplessness. Further, addressing barriers to change using the concept of ambivalence by recognizing how behaviour is controlled by both limbic as well as executive brain systems can help patients sustain recommended behaviours. Finally, the concept of readiness normalizes the fact that change is hard and can provide a pathway to support individuals when they drift toward not being ready to change.

**Conflict of Interest Statement**Michael Vallis has received speaking and consultation fees from Abbott, Abbvie, Bausch Health, Lifescan, Novo Nordisk, Roche Diabetes Care. Emma Boyland has undertaken paid consultancy for WHO Europe on projects unrelated to the current paper. Elpis Vlachopapadopoulou is a principal investigator for clinical trials sponsored by Ascendis, OPKO, and Amgen and has participated in advisory boards for Ascendis, Novartis, Novo Nordisk and Pfizer. Daniel Weghuber has received consulting honoraria from Novo Nordisk A/S. Eva Erhardt, Margherita Caroli, Marie Laure Frelut, Artur Mazur, Denes Molnar, Gabriel Torbahn, Susanne Ring-Dimitriou, Rasmus Stenlid, David Thivel, have no conflicts to declare.

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Michael Vallis drafted the paper and coordinated the edits based on author feedback. Emma Boyland, Margherita Caroli, Eva Erhardt, Marie Laure Frelut, Artur Mazur, Denes Molnar, Gabriel Torbahn, Susanne Ring-Dimitriou, Rasmus Stenlid, David Thivel, Elpis Vlachopapadopolou, and Daniel Weghuber contributed to the themes, edited drafts of this paper, and approved the submission.

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