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Title: Living on a Razor's edge: experiences of mothers caring for a son on synthetic cannabinoids in Malta

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Abstract:

Various studies have explored collectively the experiences of carers of individuals using illicit substances. Yet such experiences vary by gender, by relationship status to the substance user, by type of drug taken and whether the substance user lives within the same household. A hermeneutic phenomenological design was undertaken with five mothers of sons on synthetic cannabinoids. These sons were receiving community mental health care following admission to hospital for episodes of drug induced psychosis. Interview data were collected between August and October 2019. The transcribed texts were analysed using Interpretative Phenomenological Analysis and interpreted using the Common-sense model. The super-ordinate theme 'Living on a Razor's edge' was extracted and consisted of two themes: 'A living Calvary' and 'Fighting a Lone battle'. The findings highlight the intense psychoemotional suffering of the mothers, who experienced anxiety and fear relating to their welfare and that of the family; helplessness at not being able to communicate their concerns to their son and shame triggered by the judgmental attitude of others. Carers primarily associated the effects of synthetic cannabinoids such as psychotic episodes, to their sons being vulnerable individuals with mental health challenges rather than due to their drug habit. The mothers expressed feeling isolated as they could not turn to any family member or friends for support. The highly volatile and impulsive nature of their son further introduced a wedge between the female carer and her spouse, children, extended family and friends. Caring for a son on synthetic cannabinoids has a significant psychoemotional and social impact on the mothers as informal carers. Hence,

there is a need for a person-centred care approach to be provided, in which the shared understandings of the mothers narratives are explored and where their needs and concerns are integrated and addressed within a care plan.

Keywords: lived experiences, carers, support, synthetic cannabinoids, interpretative phenomenological analysis.

What is Known about this topic?

- Carers of substance users experience psychoemotional suffering, social isolation and associate bad company with synthetic cannabinoid use.
- Individuals taking synthetic cannabinoids have been presented as having a changed personality, disinterest in daily life and lack social connectiveness.
- Individuals using synthetic cannabinoids have been found to resort more frequently to verbal and physical aggression.

What this paper adds?

- Mothers attributed their son's symptoms e.g., psychosis to having a mental health condition, rather than their drug habit.
- The mothers struggled emotionally due to the challenging behaviour and psychotic symptoms of their son and they did not seek support.
- Interventions in carers should target specific domains of the Common -sense model, namely the emotional domain and the following cognitive domains: consequences, causal and perceptions of control.

1 Introduction

The advent of new psychoactive substances, especially synthetic cannabinoids (SC) have proven to be an increasingly popular option among drug users (Kassai et al., 2017). Synthetic cannabinoids (SC) form part of Novel Psychoactive Substances (NPS), which are a group of illicit substances most often referred to as ‘legal highs’ and which mimic the effect of traditional drugs, while avoiding and bypassing legal penalties (Bonnici et al., 2017). SC are most commonly found in the form of solids (plant matter) which are sprayed on, as well as in liquid form which can be vaped or smoked by applying the liquid on a cigarette or anything that can be smoked. It is difficult to quantify the strength and potency of SC as it is continuously changing, however a new strain of SC called AMB-FUBINACA is reportedly eighty-five times more potent than the traditional cannabis (Wilkins & Rychert, 2018).

Although SC poses an attractive option, its use has a substantial mental, physical and behavioural impact on the user (Salani & Zdanowicz, 2015). Mental health implications include a lost sense of self (Kassai et al., 2017) and psychotic symptoms ranging from delusions, hallucinations and severe thought disorder. Challenging behaviours such as manipulation, aggression, unpredictability to sporadic drug misuse and neglect of personal duties are also often demonstrated (Velleman et al., 1993). The use of SC also has physical implications including renal impairment and an increased blood pressure (Gray et al., 2016).

Various studies (Arcidiacono et al., 2009; McCann et al., 2017) targeting the carers of individuals with problematic substance use, have highlighted the diverse challenges faced. Such challenges include an increase in family arguments and aggression, apart from striving to manage issues such as isolation and stigma. However, providing care to a person specifically

abusing of SC poses additional challenges to the carers, as they resort even more frequently to verbal and physical aggression than individuals abusing from substances such as alcohol and opioids (Ergelen et al., 2018). Yet, relevant literature to date has either focused on the lived experiences of individuals taking SC (e.g., Kassai et al., 2017) or on the carers of individuals abusing of alcohol and/or illicit drugs. Furthermore, such studies often fail to consider that carer experiences vary by: relationship status (e.g., parent/spouse); gender (e.g., mothers reported to be more supportive-permissive-tolerant) and whether the substance user-carer dyad live within the same household.

Hence, this study targets a lacuna in the extant literature by providing an in-depth analysis of the lived experiences of mothers whose sons were using SC and who live within the same household. The findings of this study were then interpreted using the Common-sense model (Leventhal et al., 1980). This model was selected as it was developed in the context of information processing of health threatening messages (e.g., mothers experiences of psychotic behaviour in their sons). In addition, it acknowledges the role of carers and the importance of exploring their personal representations when facing a ‘threat’. Such representations have been identified as key to understanding carer outcomes relating to their quality of life. Based on this model, emotional (e.g., experiencing fear) and cognitive representations (e.g., perceived impact of the health threat) are construed by the carer and are processed in parallel. These representations reflect the carers’ interpretation of the health threat and can be a result of internal cues such as the experiencing of psychotic episodes in their son or external cues such as sources of information. It is hoped that the information generated can inform the formulation process of interventions and personalised plans of care that target the needs and concerns of these carers.

2 Methods

2.1 Study Design

The qualitative phenomenological research design chosen was Interpretative Phenomenological Analysis (IPA) since it enables the researcher to acquire a deep understanding of the unique phenomenon for the participant.

2.2 Participants

Eight participants were initially approached to participate in the study through purposive sampling. It was decided to target a homogenous and small sample size (typical of IPA studies) to enable an indepth exploration of divergence and convergence in participant responses. Five mothers agreed to participate with three declining for personal reasons. Inclusion criteria consisted of mothers of an adult son who: (i) has taken SC but was not on other drugs; (ii) were being followed up by a community mental health team following a hospital admission due to drug induced psychosis; (iii) was living in the same household as the informal carer. Four mothers were in a stable relationship, whilst the remaining carer was a widow. The carers ages ranged between 35-65 years. Three of their sons were still currently using SC, while the other two sons were abstinent from SC for the past six months.

Categories of age range are provided for each participant in Table 1 to safeguard participant confidentiality.

Place Table 1 Here

2.3 Data collection

In-depth semi-structured interviews were conducted by the first researcher (J.D) and in the setting as requested by the participants. The interview schedule consisted of seven open ended

questions that prompted and promoted deep sharing of reflections on the mothers' experiences of caring for a son who used SC; the manner in which they tried to cope with this situation and regarding any support that they received. Interviews were conducted in the Maltese language, and interviews lasted between 45 to 90 minutes each. The use of probes such as "what are your concerns?" and "how did such a situation affect you?" were employed when the need for additional information was required. Interviews were audio-recorded and transcribed verbatim.

2.4 Data analysis

The primary researcher (J.D) opted to carry out the analysis by following the guidelines provided by Smith et al. (2009). This consisted of immersing in the data through several readings of each transcript and the noting down of any initial thoughts. Initial note taking was undertaken that explored the language used by the participants; the context of their narratives (their lived world) and any abstract concepts that would assist the researcher in interpreting any patterns of meaning in their accounts (Smith et al., 2009). This was followed by the observation of any patterns and connections across the development of the emergent themes. Finally, the researcher proceeded by making connections between the emergent themes and writing them up in a detailed, logical and inclusive narrative account which elucidates an in-depth explanation of the whole text. The second author (J.S) then contributed through a joint review of the transcripts, following which agreement was reached on a final set of themes. A reflective diary of field notes was also kept in which the researcher could reflect on preconceived assumptions, expectations and observations throughout the research process.

2.5 Ethics

Ethical approval to conduct this study was granted from the relevant university research ethics committee. Confidentiality was ensured by allocating pseudonyms to the participants whilst data collated was stored in an encrypted format on a password protected computer.

To avoid any coercion, two mental health nurses supported the recruitment process by approaching the potential participants. These nurses were asked to ascertain that participants recruited had sons who were solely making use of SC.. They then provided potential participants with an information letter delineating their right to withdraw from the research without the possibility of any negative repercussions on themselves or their son and that participation was voluntary. Sufficient time was provided to enable the participants to come to an informed decision. Following which those five carers who expressed their willingness to participate completed a consent form. Avoidance of harm was also paramount and participants were informed that should they experience any psychological distress due to participation in the interview, the service of a clinical psychologist was available.

2.6 Rigour and trustworthiness

The model by Yardley (2000) was applied to address the issues of trustworthiness. This model is based on the following criteria: (i) sensitivity to context; (ii) rigour and commitment; (iii) transparency and coherence; (iv) impact and importance. Sensitivity to context was ensured through the provision of verbatim extracts to provide a voice to the participants and enable the readers to understand the interpretations made within a Maltese sociocultural context. Commitment, rigour, transparency and coherence relate to a thoroughness in data collection, analysis and in the coherent and detailed reporting of the research process in conjunction with the rationale for decisions taken. The final principal, impact and importance, was addressed by

generating information on the lived experience of mothers having a son abusing from SC, that is also a phenomenon of contemporary interest.

3 Findings

Table 2 presents details regarding the superordinate theme, emergent themes and subthemes. The superordinate theme ‘Living on a razor’s edge’ incorporates the reality of these mothers who find themselves living in a critical, uncertain and solitary predicament prior to their son’s first admission to a psychiatric hospital for drug induced psychosis. The emergent themes ‘A living Calvary’ describes the intense psychoemotional impact experienced by carers, whilst ‘Fighting a lone battle’ reflects the deep sense of isolation experienced during this period.

Place TABLE 2 Here

3.1 A living Calvary

The first emergent theme extracted namely “A living Calvary” was a metaphorical expression voiced by one of the mothers to describe the intense psychoemotional suffering experienced. Carers described how their son began to show signs and symptoms of mental health problems relating to their drug habit. Such signs and symptoms consisted of increased suspicion; isolation and withdrawal; engaging in bizarre behaviour and experiencing auditory and command hallucinations, as described by Kate:

“He was confused ... he used to hear voices ... he thinks he is God ... and the devil speaks to him ... he wants to extract his brother’s heart out ... he used to have a lot of hallucinations” (Kate)

Due to the severity of such psychotic features, the mothers perceived that their sons had lost the ability to reason or to acknowledge that they have a problem. This scenario triggered feelings of anxiety and fear for their son's well-being but also that of their family. It also instigated feelings of helplessness, as they could no longer communicate their thoughts and concerns to their sons. One respondent commented:

“He even lost his speech ... I would speak to him about something and he would answer back about something else ... he would not make any sense ...I couldn't get through to him...I was at a total loss” (Grace)

The presence of such psychotic episodes at times led to the involuntary hospital admission of their sons. The mothers expressed anger, humiliation and resentment at the commotion created by the police when collecting their son. They emphasized that their sons were not criminals and that their erratic behaviour was primarily due to their mental health problems. In fact, mothers referred to their sons at times as patients. The commotion created by the police presence was also perceived as instigating a negative judgmental attitude towards their son and the family. Hence, they reiterated the importance of including mental health professionals in such circumstances.

“You begin to see that one [neighbour] is peeping out of the window, the other one comes out of the house to see ... you see the police car, your son is entering [the car] handcuffed ... blue lights [of the car sirens] lighting up the street, if there are mental health problems it doesn't mean that they're criminals. If you only know how upsetting it is for the family, upsetting for the patient ... with all due respect, the police do their work but they are not mental health professionals...” (Grace)

The mothers also strived to continuously monitor their sons, fully aware that the situation was highly volatile. They were aware that their son's bedroom served as their haven where SC were consumed. One respondent commented that:

“My son used to lock himself in his room, the door was always closed. I was always checking up on him to see what he was doing ... I always feared the worse” (Maria)

Yet this situation was further compounded by the manipulative behaviour of their sons. Such experiences included: deception, lying, threatening behaviour and being rebellious, which left their mothers feeling upset, fearful and emotionally exhausted. Kate shared this experience:

“I worry a lot and you say to yourself: is he going out to smoke [the SC]? ... he comes back in, always denying that he smoked ... well I am always worrying about him ... my mind never stops ... he will get mentally ill again...” (Kate)

Feelings of dread and fear were also experienced by the carers as they were constantly hounded by their sons for money. One carer in particular (Grace), described how she dreaded the dawning of a new day that commenced with her son demanding money. Moreover, these mothers struggled knowing the money provided would only serve to finance their son's drug habit, as exemplified in the following excerpt:

“I was afraid when he would wake up ... the first thing that he would do was request money to go and buy it [SC] ... his mind was fixated on buying it [SC] ... he used to wait for the telephone call alerting him to meet around the corner to buy the cursed synthetic ... he stays

3 minutes away from home and returns ... locks himself in his room and I would think that he is going to consume it ... those were very challenging times ...” (Grace)

The mothers explained that they often gave in to their sons demands because they felt threatened. Their sons were described as resorting to profane language and threatening behaviour and violence towards the carer if their demands were not met. Such scenarios exposed these mothers to a life of terror, fear, physical pain and humiliation and the experience was often worse when their spouse was not present to defend them:

“There were both physical and verbal arguments ... if I refused to give him money he used to curse the house with profanity and become aggressive ... sometimes I used to be at home and he would begin banging and he used to frighten me ... I used to give him money so that he would back off... but it just isn’t right that I give him money for drugs ... he began to treat me worse when his father was not present [to defend her]” (Jane)

The mothers also reported that at times their sons would disappear for days without informing or maintaining any contact. This would leave them burdened with concerns regarding their son’s safety, such as whether they were hanging out with ‘bad’ company or whether they were overdosing on their own. Josette described struggling with these thoughts especially at night and feared that her son’s drug habit could end up killing him:

“He [her son] used to spend nights away from home ... It drove me insane ... insane because he used to switch off his mobile phone and you wouldn’t know where he is ... what will

become of him ... and God forbid that he takes a dose more than he can withstand and he'll go to his creator [God]... ” (Josette)

3.2 Fighting a lone battle

The second emergent theme named “fighting a lone battle” described the isolation carers experienced whilst supporting their son abusing of SC. This also included the interactions of these carers even with family and close friends. In the following excerpt, Jane explains how the volatile and impulsive behaviour of her son created a wedge separating her both from her daughter and that of her elderly mother:

“Well my daughter no longer visits us with her children ... I am deprived of seeing my grandchildren ... I haven't got any siblings... my mother is old and I don't tell her anything as I would send her to her grave with worry ... I don't want to take my son near her because he would rob her or do something else for sure ... I have ended up alone ... fighting alone...”
(Jane)

Caring for a child who used SC also posed a negative impact on the relationship between spouses. The mothers expressed reluctance to expel their sons from home as they could end up homeless or in bad company, whilst their spouses insisted that such an action was necessary to regain the peace of mind, tranquillity and normality within the family. Such discordance led to conflicts between the spouses themselves, a fact that further increased pressure and distress on the female carer, as exemplified in the following excerpt:

“Once he started abusing [SC] he lost everything even respect towards the family, he was not considerate to anyone, I would end up arguing with my husband ... he would tell me not to let him into the house but I just couldn’t bear to leave him out ... my husband has a point however, so do I as his mother ...it is true that if there is no discipline he [their son] will continue to abuse ... however a mother is always a mother” (Kate)

Apart from causing disruptions within the immediate family, the mothers also reported that their social interactions with others, such as friends was also affected. The carers explained that the impact of caring for a person who has used cannabinoids totally overwhelmed their lives, resulting in a loss of interest to engage in any activities:

“We used to go for barbeques with my family and relatives ... we don’t anymore... everything has stopped but the others still meet ... now everything has just totally ended ... we have lost interest in everything” (Josette)

4 Discussion

Extant qualitative research to date focuses on the carers of individuals abusing from illicit drugs, however in such studies (e.g., Arcidiacono et al., 2009; McCann et al., 2017) the experiences of carers having a different status to the substance user (e.g., spouses, parents, siblings, children) are analysed collectively together. However, this collective interpretation of carer experiences fails to acknowledge that these experiences often differ by relationship status to the person using illicit drugs. For instance, spouses of persons taking illicit drugs appear to use more control strategies, are more willing to ask for external support and are more able to distance themselves from their spouse, to safeguard other family members (Arcidiacono et al.,

2009). Conversely, parents are described as being primarily focused on assisting their child and are reported to use fewer coping strategies in comparison to other carers.

Carer experiences are also reported to differ by gender, with mothers tending to be more supportive and permissive to the child who was abusing than fathers. This is corroborated in the present study for mothers of a son using synthetic cannabinoids. Another aspect that influences carer experiences is whether the child who is taking drugs lives within the same household as in such cases the carers are reported to experience greater financial, relationship and emotional challenges (Benishek et al., 2011). Consequently, the present research targets the lacuna in extant literature, by exploring the experiences of a homogenous sample of mothers having sons who *specifically* used SC and who lived within the same household. These experiences shall be interpreted within the context of the Common-sense model that describes how individuals form representations of their experience from 3 sources namely: the general pool of lay information available regarding the illness/condition ; expert sources of information and current and past experience with the illness or condition (Hagger et al., 2005). As demonstrated in the present findings, this study focuses on the mothers' representations of their experience prior to reaching out for professional help with their son's involuntary admission to a psychiatric hospital.

The following section (section 4.1) discusses the psychoemotional implications of caring for a person who uses SC, whilst Section 4.2 discusses the isolation that mothers experience in the process.

4.1 A living Calvary

The mothers in the present study compared the intense *emotional* toll experienced to a “a living calvary”- a metaphor used that vividly expressed the intensity and depth of their suffering. It is

an expression that is commonly used in the Maltese language and which is associated with Christian religious beliefs, namely the intense suffering experienced by Jesus Christ during the crucifixion on Calvary. The mothers struggled intensely under a gamut of emotions and expressed feelings of discouragement and worry due to the substance users' challenging behaviour and their struggles in caring for their son, whilst also striving to protect other family members from him. Participants also highlighted the humiliation experienced at seeing their son escorted involuntarily to a psychiatric hospital. Such involuntary admissions to the psychiatric hospital occur in Malta, when the individual is deemed to be a risk to self, to others or are at risk for a further deterioration in mental health. Consequently, the mothers reiterated the importance of having mental health professionals present in such circumstances, as they are trained to deal with individuals displaying psychological and behavioural challenges. The carers also described that the substance users would often leave the household for days, avoiding any contact with family members and withholding information on their whereabouts. This finding concurs with that reported in various studies, however for drug and/or alcohol users (Orford et al., 2010; Velleman et al., 1993). In this context, the carers struggled with a gamut of feelings including concern, worry, anxiety, and fear regarding whether others may take advantage of their son's vulnerability. This highlights the need for enhanced access to emotional support services that target stress and burden among these carers (Slaunwhite, Ronis, Sun, & Peters, 2017).

In addition to the emotional processing of a threat, carers also conducted *cognitive processing* to understand and make sense of their experience. The present study applies the following cognitive domains from the Common-sense model namely: (i) identity (ii) causes; (iii) consequences, and (iv) control (Leventhal et al., 2003) to evaluate the experiences of these mothers. The 'identity' domain refers to giving a 'label' to any symptoms experienced, known as the 'symmetry rule'. This is exemplified with mothers attributing symptoms expressed in

their son to an illness, for instance where the hallucinations experienced were associated with their son's drug induced psychosis. The 'causal' domain incorporates identifying the cause of their son's condition. In this study, the participants attributed their son's drug habit to being overwhelmingly vulnerable and having a mental illness. In fact, when referring to their son they used the term 'patient' with a mental illness. Conversely, this finding does not concur with that identified by Arcidiacono et al. (2009) where parents attributed their child's drug and/or alcohol habit primarily to external others, such as bad company. This difference in attribution may be influenced by the fact that all participants in the present research had required a hospital admission for drug induced psychosis. Furthermore, by attributing their son's behaviour to a mental illness the carers may circumvent blame and guilt away from their son or themselves and onto something beyond their control. This finding highlights a need for psychoeducational interventions for these mothers where information is provided about synthetic cannabinoids and their associated effects, including symptoms of psychosis.

4.2 Fighting a lone battle

Participants in this study strived to indicate the intensity of their experience and the toll on them personally through use of terms such as 'fighting' or a battle'. These lone 'battles' were fought as the mothers strived to safeguard their son, themselves

and other family members.

The Common -sense model (Leventhal et al., 1980) highlights the need to focus on the perceived 'consequences' experienced by the carer in providing support and care. The mothers highlighted the social consequences both on themselves and on family members. Findings from the present study concur with that of various authors on the carers of drug and/or alcohol users (Arcidiacono et al., 2009; Jackson et al., 2007; Orford et al., 2001; Velleman et al., 1993) demonstrating that carers tend to isolate themselves from family members and friends, especially at times when the substance user was taking illicit substances. In

fact, such carers tend to be reluctant to seek support, for fear of being judged a 'bad' parent and to avoid bringing shame on the family, should others become aware of their son's condition (Orford et al., 2010). Caring for an individual on SC was also reported to place a wedge between spouses due to discordant views relating to their son's care. This concurs with the study of Arcidiacono et al. (2009) where female carers perceived their role to be one of supporting their sons and ensuring that they do not struggle on their own, even though this impacted them negatively both physically and mentally. Conversely, the male figure (father) tended to disengage from the substance user and focused on the overall welfare of the family, hence portraying themselves as being 'strong' and the leader of the family (Kaufman, 1981). The impulsive and aggressive nature of their son however also impacted siblings, even those not living in the same household, who avoided visiting their parents to safeguard themselves and their families. Within this scenario, the impact on the mothers was aggravated due to the 'loss' of the son that they once knew and due to the wedge introduced between them, their family members and friends. Hence, whilst carers for various chronic illnesses often cite family members as a source of support (Fenech & Scerri, 2013), this was not identified for the mothers of individuals using SC, who described a very solitary and lonely existence.

Another cognitive domain cited in the common-sense model is that of 'control'. The mothers described a situation where they felt at a loss and uncertain on how best to handle the discovery of drug use in their families. They expressed helplessness and an inability to communicate effectively with their son. As a consequence, the mothers perceived that they could not exert control over their situation. This lack of control is linked to psychological distress, more negative views of the impact of care (Kuipers et al., 2010) and perceiving the condition to be more serious (Hagger & Orbell, 2003). Hence, the constant 'battle' experienced by these mothers, instigates both a parallel processing of emotional representations (e.g., feeling helpless) and cognitive representations (e.g., interpreting the impact of caring on themselves and family members) in their effort to find meaning and cope with their situation.

4.3 Limitations

As typical of IPA research, the study was undertaken with a small sample of participants and hence research findings are not generalizable. However, the aim of this study was not to generalize the study findings but rather to collate in-depth accounts of the lived experiences of mothers of individuals using SC. In addition, the frequency of or length of SC use was not considered and may have had an impact on the experiences of the carers. There is also the need for further studies that explore the experiences of male carers of individuals abusing from SC, especially when considering that the present study highlights the conflicting perceptions between the couple.

5. Conclusion

Extant literature tends to focus on the experiences of carers in general of persons taking drugs/alcohol. Yet such experiences vary by relationship status to the person using illicit substances and whether they live in the same household or not. Moreover, although caring for an individual on SC poses additional challenges due to the frequency of aggression experienced, yet there is a dearth in literature on the experiences of such carers. This study contributes by focusing on the experiences of mothers of sons taking SC and living in the same household.

This study also demonstrated that the mothers of individuals using SC primarily perceive their sons as ‘patients’ or vulnerable persons with mental health challenges. This probably relates to the expression of drug induced psychosis in their sons. Hence, these mothers reiterated the

importance of including mental health professionals in supporting their sons on their road to recovery.

The study demonstrates the significant psycho-emotional and social impact on the mothers. Hence, there is a need for psychosocial and emotional interventions that target the feelings of isolation and the considerable psycho- emotional impact of caring. Thus, opportunities should be provided for self-development through stress management, assertiveness skills and psychoeducation relating to the drug, its associated effects and treatments available. Assistance may also be provided by developing links to a variety of relevant support groups available, where such carers do not fear being judged.

As professionals it is of importance to understand and work with the beliefs of such carers in order to address their related needs and concerns. Through the provision of person-centred care professionals approach each care situation as a unique interaction that involves developing an understanding of the beliefs and values of individuals such as carers, including how they make sense of their experiences (McCance & McCormack, 2017). The personalized information generated can be integrated in any plans of care provided, through actively negotiating and evaluating any intervention plans with the carers.

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Conflict of interest

The authors have no conflict of interest to declare.

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