

UNDERSTANDING NON-FATAL ECSTASY-RELATED COLLAPSE

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I suppose I will just start by saying that I am talking about collapse with ecstasy and it is important, I think, to be talking about some of the harmful aspects of this; but naturally collapse is just one of the bad things which happen sometimes when people use a drug which can otherwise be very enjoyable.

It is important to understand collapse, I think, because from the UK context, when we look at the epidemiology, we see that the number of ecstasy deaths appears to be increasing. We also see, very clearly, that the price of pills is falling year on year and because when you try to understand what is going on when people die from ecstasy, our understanding of that is incredibly poor. Yes, we can talk about heatstroke; Yes, we can talk about hyponatremia (when people get the information wrong and drink too much water), but when we are trying to give detailed, concrete guidance and have any kind of insights as to why, on these very rare occasions, things do go tragically wrong in that way, we are not very clear; we cannot say so much about that as we would like.

(Referring to screen) This is just a slide taken from the largest study of so-called 'ecstasy fatalities', conducted in the UK by Schifano et al. Here you can see a very clear increasing trend of ecstasy-associated deaths, year on year, although one of the things within their data shows that (this is data taken from Coroners' reports) what the papers are referring to as 'ecstasy-related deaths', in fact relate to individuals who have ingested a number of substances, including heroin and other opiates, sometimes in combination with alcohol, which in their own right are sometimes sufficient explanations as to why people may die; there is often little opportunity to probe behind these deaths to find out exactly what went on. So we do have an increasing trend of deaths associated with ecstasy, but exactly how many are directly attributable to ecstasy is harder to say.

(Referring to screen) This is data taken from the MixMag study, which is a self-completion questionnaire conducted within the UK, year on year, in the biggest clubbing magazine that we have there. Important points to notice are: the price of ecstasy, per pill (it may make any ecstasy users in Australia a bit jealous) in 1999 the survey showed an average price of £7.00 per pill, the year before last showed a drop to £3.00 a pill and in last year's data it was even cheaper still. You will also notice that the number of pills used per session, on average, seems to be creeping up.

So we have increasing deaths, decreasing price of ecstasy and a probable increasing number of pills being used in a session. A session can obviously be just a few hours out on an evening, though some people's session range from Friday lunchtime through to Sunday night and sometimes beyond; people obviously use in different ways. Obviously we think about cause of death, heatstroke most prominently, and it is very hard to find ecstasy users who have not heard of heatstroke as a possible risk associated with ecstasy and who are not aware of some of the basic harm reduction techniques.

Obviously though, if you are using a stimulant drug in combination with other stimulants that are, in their own right, able to sometimes trigger cardiac arrest, then I think one has to consider whether there is sometimes an additional factor or an additional risk of using ecstasy in that way that is contributing to some fatalities. Also when viewing the English data, where we are finding that people have also ingested ecstasy, it is worth considering whether some of the ecstasy deaths reported are spurious association. So I think we have to look quite hard at any epidemiology that is talking about ecstasy deaths, in order to be really clear about what is going on and whether there are other mechanisms that may explain what is going on as well - factors that are not generally discussed within the literature. One of the things that is a big challenge to people trying to understand ecstasy-related death is the fact that, thankfully, they are relatively rare, even though we are showing an increasing prevalence of them in the UK, they are still very rare relative to the number of doses of ecstasy that are being consumed.

It is a long-standing understanding that the Coroners' data that is available; the accounts that are given when someone dies, especially of ingesting illicit drugs; the accounts that will be given by people who have possibly sold them the drugs or used the drugs with someone; will be cautious, hesitant and will omit certain details, so the data that is available within Coroners' records is often very flawed. Different case definitions are used and so studying coronial data is problematic and a lot of the questions that you would like to ask in detail, of the person who is dead, about: how hard were you dancing? What was the club like? What else were you using? Had you been sleeping well that week? Did you have a bit of infection at the time? Anything like that, you cannot ask those questions to somebody who is dead. So there are a lot of details that inform possible hypotheses about what may have triggered a death in somebody who has been using ecstasy regularly, that are unavailable for scrutiny. So are there things that we can do that will improve our understanding of what is going on here?

The MixMag survey is a self-completion questionnaire that was put out in the clubbers' magazine. Typically we get about a thousand responses a year. We put in a question about collapse, figuring that, when your body collapses this is obviously not the same as dying, but it is a strong signal that you are pushing your body to the limits, and that factors which contribute to collapse may also be able to give us some insights into what happens when people die after using ecstasy. But we did not know how many people collapsed when using ecstasy.

We suspected, just from anecdotal accounts and so forth, that people collapse a lot more than they die. And then three years ago, we asked the question about the rates of collapse and we found that something like 5% of people said that they had collapsed while using ecstasy. So last year, we included a question about collapse, with additional structured information about what drugs people had used at the same time and so forth, and we also said participants to willing to be interviewed about their experience to submit their name and contact details, and a number of people responded to this.

Now clearly there are lots of things here to take issue with. Do people all define collapse in the same way? No, certainly not. Is ecstasy a constant commodity? No, obviously not. But nevertheless, in a self-completion questionnaire, within the

limitations of what we are able to do, this seemed like one of the better ways of phrasing it. And so what we found, consistent with the previous year and two years prior to that, 63 respondents out of 1134 said that they had collapsed, so about 6% of people, in this sample of hard-core clubbers. (Do not in any way think that this is your representative sample of clubbers. These are in the main, people that are much more extensively involved in clubbing, probably consuming higher levels of drugs than the average clubber.) Nevertheless, 6%, quite a substantial proportion of people said they collapsed while using ecstasy in the past year.

A number of those involved gave us names and phone numbers; some of which we have been able to follow up on and some of which I am still in the process of following up on, so I am presenting this to you as very much 'work in process'. I am still at the stage of phoning people back for the 10th time saying "Can we sort out a time when you can spend an hour talking on the phone?" and dealing with answer-phones and so forth, but we have got 10 interviews completed so far, where we have asked people a number of questions: contextual information about the club, that night, their previous week's ingestion, actually what happened during the collapse, what happened after the collapse, and so forth.

I am working from a semi-structured interview guide, so I have a number of topics that I try to run through with people. I ran the guide past a number of different experts in the field, saying: "if we are thinking about collapse and fatalities, what sort of questions should we be sure that we consistently include if people do not volunteer these issues. So that is the sort of data that we have. The structured questions that we built into the questionnaire, that relate to that 6% people, one of them is about "what were you using at the same time?" Only one person said: "I was only using ecstasy. I was using nothing else when I collapsed." Only one person said: "I can't remember what I was using at the same time." In fact, what is coming out from the qualitative interview data that I am gathering, is that when people collapse it sticks in their mind as a bit of a different night out and they think hard about what has been going on; they try to explain how that happened and most people can give quite impressive accounts of large aspects of the history.

(Referring to screen) A lot of alcohol there, as you can see, cocaine cropping up a lot and modest numbers of people consuming GHB. Some Ketamine, and Cannabis present of course, and some Amphetamine, which I think is particularly interesting and does come through in the interviews.

So people using a range of substances (referring to screen) a slide like this of course does not tell you about the *sequence* of people's drug-taking and the intensity of them: "Were you doing everything at once or spreading it out more sensibly?" But nevertheless, this is an indication of what people were using at the same time. Strikingly, in these data, there is nobody saying they were using heroin or any other opiates at the same time. In the other category the other things that crop up, that we did not ask for, were things like mushrooms and poppers, and one person reported that they used 4 MTA – 'flatliners'.

One of the other key things we asked about in the structured questions was: "how many pills did you take at the time?" We also have data on people's usual consumption within a session, for the whole sample. (Referring to screen) And I

think one of the very obvious things that jumps out of these data is: on the left-hand side you have the people who collapsed, talking about the number of pills they thought they did on that evening; and on the right-hand side you have a comparison with the MixMag sample's usual consumption when they go out clubbing. So, the means are skewed a bit by some very high consumers, but there is a medium number of 5 pills among those who collapsed; medium number of 3 pills among the general sample.

The range of pills used on the night that they collapsed, ranging between 1 and 73 pills, is an outrageous number of pills to be taking over a session. Of course, some people's sessions normally mean that this is more than one day. Looking at the high end, we have over a quarter of people using 10 or more pills in that particular session, in the collapsing sample, whereas only 1.7% (just single figures of people) using 10 or more pills on an average session from the rest of the sample. We asked about attendance by paramedics or hospital at the time of collapse and found that 30% of the sample who collapsed were either attended to by a paramedic or went to hospital.

(Referring to screen) These are just little summaries of what people said, so, here we have got a 28-year old female from Glasgow. Her first one ecstasy-related collapse just goes to show how you have to be so careful about what people give you – 6 or 7 bottles of beer, couple of lines of coke, 2 or 3 pills and then as she is telling me this story, she said “I went back to my friend's house and then I did a couple of ‘eggs’, ‘jellies’, temazepam, and probably did about 10 of those and then I passed out.” So she has taken lots of temazepam and she has responded to a question about ecstasy-related collapse. So this is not relevant to understanding ecstasy-related collapse in my opinion, this is just somebody who has just done too many benzos. And then, almost as an afterthought, she added “Yeah, another time though, just a few months ago, I did 4 or 5 pills, they were ‘smilies’, so I did not drink anything, and I did not smoke anything, no Charlie, nothing like that, went out clubbing, back to someone's house afterwards. When I got back there, all of a sudden I started getting these bolts of lightning going through my head, really severe bolts of lightning, scary sensation”, she went to get out of the room, collapsed, thought she was out for 10 or 20, 20 or 30 seconds. Her friends said that she was shaking about - you get various bits of secondary data like this, witness accounts from friends saying what happened – “I was foaming at the mouth, I bit my tongue and lips.” It seems as though she is describing a *grand mal* seizure, I do not know for sure, but then she went on to explain “I did have epilepsy when I was a child, I was controlled on Tegretol, had not had any of that since I was 16, I am now 28”, so she had been free of fits without medication for 12 years, but then since that night out she had several fits and was now back on Tegretol. So it seems as though that night, in some way, seems to have re-initiated epilepsy.

I have about another 9 cases here, all very different, where I am just trying to develop hypotheses about exactly what might have gone on, so find me later if you are interested to help me think through what might be going on with these people who collapse.

Thank you.