

Compassion or stigma? How adults bereaved by alcohol or drugs experience services

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What is known about this topic

- Compassion is central to good health and social care.
- Scandals have highlighted lack of compassion, especially towards stigmatised and/or vulnerable service users.
- Structural reforms to services can undermine or enhance compassion.

What this paper adds

- Stigma and 'othering' undermine compassion.
- Compassion, stigma and professionalism may be linked theoretically.
- Irrespective of structural reform, small acts of kindness based on symbolic kinship reduce service users' experiences of stigma.

Introduction

In a number of countries, care that is less than compassionate has been identified as a problem in healthcare (Youngson 2010, Lown *et al.* 2012). In the UK, official reports of poor care in NHS hospitals, home care and care homes have been picked up by national media and policy makers, so that 'compassionate care' has become a policy buzzword. While most practitioners strive to provide good care, scandals have raised questions about whether healthcare re-organisation – such as government-initiated targets, marketisation or the commodification of care

Abstract

How to promote compassionate care within public services is a concern in several countries; specifically, some British healthcare scandals highlight poor care for service users who may readily be stigmatised as 'other'. The article therefore aims to understand better the relationship between stigma and compassion. As people bereaved by a drug- or alcohol-related death often experience stigma, the article draws on findings from a major British study, conducted during 2012–2015 by the authors, of people bereaved in this way, in order to see how service provision can be improved. One hundred and six bereaved family members were interviewed in depth about their experiences of loss and support. Thematic analysis developed theoretical understandings of participants' lived experiences. This article analyses our data on how bereaved people experienced stigma and kindness from practitioners of all kinds. We found that stigma can be mitigated by small acts of kindness from those encountered after the death. Stigma entails stereotyping, othering and disgust, each of which has emotional and cognitive aspects; kindness entails identification and fellow feeling; professionalism has classically entailed emotional detachment, but interviewees found cold professionalism as disturbing as explicit disgust. Drawing on theories concerning the end of life, bereavement and emotional labour, the article analyses the relationship between stigma, kindness and professionalism, and identifies some strategies to counter stigmatisation and foster compassion.

Keywords: alcohol, bereavement, compassion, disenfranchised grief, drugs, professional detachment, stigma

(Lloyd *et al.* 2014) – undermine compassion. What is rarely commented on, however, is that scandals have disproportionately involved two specific, overlapping groups with whom practitioners may not easily identify: frail elderly people near the end of their life (Francis 2013), and those displaying cognitive traits or physical symptoms that may readily be stigmatised (Flynn 2012). This raises the question whether compassion might be undermined by the stigmatising and 'othering' of particular patients and service users.

To assist research-based discussion of how to care compassionately for stigmatised service users, this

article reports some research findings from a particular group of people who are often seen as 'other' and may feel stigmatised, namely adults bereaved as a result of alcohol or drugs. The overall aim of our research was to explore the experiences of this neglected group in order to improve policy and practice. This article's specific aim is to learn from them: (i) what they do and do not value about how practitioners respond to them; (ii) how stigma and compassion operate; and (iii) how practice can be improved – both with this particular group and in public service more widely.

The families of substance users [Language can inadvertently stigmatise (Broyles *et al.* 2014), so we have chosen our language with care, avoiding 'substance abuse' and 'addiction'.] are often either ignored in treatment programmes, or pathologised as 'co-dependent' or dysfunctional, part of the problem rather than of the solution. The stigma attached to the substance user easily gets transferred to the family. Orford *et al.* (2005) have challenged this, highlighting how family members have their own needs for support as they struggle to cope with what alcohol or drugs are doing to their family (Barnard 2007; UKDPC, 2009). When users die, families 'frequently attract public interest and media attention, but supporting the bereaved in their grief is rarely of paramount concern' (Guy & Holloway 2007, p. 86). Some drug and alcohol treatment agencies work with families but typically lose contact once the client has died; bereavement agencies rarely have expertise in drug and alcohol issues. Across the globe, only four studies (Da Silva *et al.* 2007, Guy & Holloway 2007, Feigelman *et al.* 2011, Grace 2012), of which three are very small, have hitherto researched how families cope after such a death (Valentine *et al.* Forthcoming).

Methods

Our 3-year Economic & Social Research Council-funded study, undertaken during 2012–2015 in Scotland and South West England, conducted in-depth interviews with 106 adults bereaved through substance use – globally, by far the largest and most diverse such research sample. The study received ethics approval from our two universities. Lacking hard information about the size and demographics of this population, we aimed not for a representative sample but for one displaying both homogeneity and variation, its size allowing some comparison of sub-groups (Table 1). Initially, convenience sampling guided recruitment, with regular review leading to purposive sampling in the latter stages; there was also some snowball sampling, particularly in Scotland. As

Table 1 Sample characteristics

100 interviews (including 6 with couples)	
Interviewees (<i>n</i> = 106)	
Gender	Female: 79. Male: 27
Mean age at time of interview	52 (range: 22–75)
Ethnic status	Most described themselves as white British
In treatment	12
In recovery	9
Relationship with deceased	Parent: 56 Child: 21 Spouse/partner (includes ex): 13 Siblings: 13 Friends: 6 Nieces: 3
Living with deceased at time of death?	No: 84. Yes: 27.
Deceased (<i>n</i> = 102)	
Gender	Male: 79. Female: 23
Mean age	38 (range 16–84)
Ethnic status	Most were white British
Mean time since death	8 years (range 1 month to over 30 years)

with other bereavement research, participants were not approached directly by the research team but either initiated contact with us or had contact facilitated by a third party such as a bereavement, drug or alcohol support group. Written informed consent was obtained from all interviewees.

The interview guide invited interviewees to describe (i) how things were before the death; (ii) the death itself; and (iii) events, coping and support afterwards. Interviews lasted from 40 minutes to over 2 hours, were audio-recorded and then fully transcribed. Analysis was thematic, combining inductive grounded theory with interpretive phenomenological analysis in order to develop a theoretical understanding of participants' lived experience. Using QSR Nvivo 10, three researchers independently coded 10 interview transcripts; the entire research team discussed these provisional codes, out of which 21 themes emerged, with a final total of 85 codes. This provided the final framework for coding and then analysis.

We coded interview data on stigma into two sub-codes ('experiences of stigma', 'disenfranchised grief'); within these, analysis identified four sub-themes that explain how stigma operates and yet could be counteracted by kindness. The first two (*stereotyping, othering*) refer to cognitions, while the third (*feeling with, feeling against*) highlights how othering is emotional and visceral as well as cognitive; the fourth (*doing your job*) identifies a practitioner style that attempts to be neutral. Link and Phelan's (2001) review article

'Conceptualising Stigma' helped us identify the first two. The sub-themes are inter-related, so quotes may illustrate more than one sub-theme, but we present each sub-theme separately in order to build our analysis.

Respondent characteristics

As in most bereavement research, interviewees were more often female, though – reflecting national statistics of substance use – the deceased were more often male (Table 1). Ages of both interviewees and deceased were diverse, as were interviewees' relationships to the deceased (e.g. parent, child, spouse, partner, sibling, niece, friend) and whether interviewees were themselves in treatment or recovery for an alcohol or drug problem. Time since death varied from a few weeks to over 30 years, averaging about 8 years. Deaths involving alcohol and/or opiates/opioids (primarily heroin or methadone) dominated, with interviewees describing many causes of death and how alcohol and/or drugs contributed. Causes of death included overdose (intended or accidental), suicide, illness (whether or not resulting from long-standing substance use), accident and homicide. While some deceased had been occasional recreational drug users, most had had a long history of extensive drug or alcohol use, several fitting the technical definition of dependence and causing long-term stress for their families.

Findings: stigma and kindness

Our findings are wide ranging (Cartwright 2015); here we present those specifically relating to compassion and stigma. From the interviews, a typical picture emerged in the days and weeks following the death. On the death being discovered, many of our interviewees found themselves plunged into complex, confusing and separate procedures, involving for example emergency and primary healthcare, police, coroners (in Scotland, procurators fiscal) and newspaper reporters – often at the same time discovering unwelcome new knowledge of their relative's lifestyle or encountering associates implicated in the death. They often presented the deceased's self in ways that protected both the deceased's and the family's reputation – a response noted by stigma researchers from Goffman (1963) onwards. All this was in addition to the 'normal' chaos experienced after any death, and in many cases no family liaison officer was provided to guide them through the maze. Personnel such as ambulance crew, police, coroners and media reporters are required to focus on the deceased rather than on the bereaved, whom they may see as sharing the deceased's

unsavoury lifestyle, getting in the way, or simply a means to providing information for police or journalist to construct their own required narratives.

Feeling stigmatised often derived not from other people's direct actions or words, but from tone of voice or body language. Direct experiences of stigma were outweighed by perceived or assumed stigma; we found less direct evidence of stigma than described in the literature (UKDPC, 2010; Adfam, 2012). But interviewees did report constantly having to deal with other people's expectations about substance use and what a user is like. Some interviewees wanted people (friends, officials, the public) to see beyond the 'addict' and know the 'truth' about the person, for example that they were a lovely person who was in turn loved and did not fit the 'junkie/alcoholic' stereotype. It is possible that some of our interviewees interpreted as stigma a practitioner's discomfort or uncertainty about how to behave, especially when the interviewee had felt their family had been subjected to years of being stigmatised as dysfunctional.

What stands out in our data is that when people had good experiences from others, it was because they met kind individuals. One daughter referred to 'those small acts of kindness that meant so much to us'. Such acts, or their absence, affected whether the bereaved person felt they mattered, or did not matter – sometimes affecting how subsequently they grieved and did, or did not, seek support. Positive examples include acknowledgement that death/investigation is difficult for the family member, police who offered a lift to the mortuary for the family to view the body, practitioners who took time to attend the funeral. Negative examples include appearing judgemental of either the deceased or the family, referring to the deceased as 'the body' rather than by name, a family doctor not contacting the bereaved to offer condolences. There were many positive reports of funeral directors (whose business stands or falls by caring for clients, and who are paid to spend hours rather than minutes helping clients through a defined, difficult period), but otherwise the picture is mixed, with no one profession standing out as particularly good or particularly bad.

We now analyse this in more detail, employing the four stigma sub-themes presented in the Methods section.

Stereotyping

We know that stigma entails labelling and stereotyping, so that all those labelled a particular way (e.g. 'drug addicts') are assumed to be similar. 'Categories and stereotypes are often "automatic" and facilitate "cognitive efficiency" ... (They) are used in making

split-second judgments and thus appear to be acting pre-consciously' (Link & Phelan 2001, p. 369). This is relevant to our study for two reasons. First, those who had died were enormously varied in who they were, what substance use meant to them and how they died, as were our interviewees' attachments to them. Yet, in the immediate aftermath of sudden death, professionals and officials typically have little, if any, time to get to know either the deceased or their family. Ambulance crew or police called to the family home may know little or nothing of who or what they may find, and may employ stereotypes to help make immediate sense of the situation. Our respondents were upset when they found themselves on the receiving end of incorrect stereotypes:

I do blame the police ... I think they thought he was just an old tramp or something. (Mother, E2a) [Interviewee code: Ea = England, interviewer (a). Eb = England, interviewer (b). S = Scotland, interviewer (c). Where interviewees mentioned personal names, we provide pseudonyms.]

By contrast, either the deceased or the bereaved being treated not as a stereotype, but as an individual, was highly valued. E2a's experience of the immediate aftermath of her second son's death was much more positive than the first:

There were two policewomen who came and they stayed and they made us tea and they comforted us [cries] ... And David was known to the police as well because he had been an addict, you know, he had been in trouble and that's awful as a mother. You feel like society looks down on you. But I didn't get that sense, no. They couldn't have been more helpful.

Professional care taken by police or by staff in the coroner's or procurator fiscal's office to get the facts of each unique death straight was also appreciated.

(The woman from) the fatal accident enquirer unit has been great. She checked it out and discovered that no this guy hadn't died in relation to that girl, she told me that and then said that there was still unanswered questions in Joe's notes and that she would do her very best to get answers for me. (Mother S14)

A simple shift of language can defuse stereotyping:

The doctor in A&E who signed his death ... he said 'This gentleman had died' and that made such a difference to us. We were upset and I thought he wasn't referred to as 'This drug addict has died', you know. (Mother, E29a)

Doctors' letters referring to 'this gentleman' or 'this lady' are a quaint feature of British medicine, according high status to patients regardless of their actual social class, but its use by this emergency unit doctor spoke volumes to the deceased's parents.

Us versus them

To turn labelling and stereotyping into stigma requires separating 'us' from 'them'. He is mentally deranged, I am sane; they are lazy, we are hard-working. 'A person *has* cancer, heart disease, or the flu – such a person is one of "us", a person who just happens to be beset by serious illness. But a person *is* a schizophrenic' (Link & Phelan 2001, p. 370). Or a drug addict, or an alcoholic. This separation between respectable us and disreputable them can extend to the substance user's family, both before and after death. Kindness, by contrast, implies connection. Ballatt and Campling (2011, p. 9) noted that *kind* is etymologically related to *kin*, so feeling connected to the other is part of kindness.

All the quotes in the previous section illustrate this. Labelling and stereotyping distance the labeller from the bereaved family, but kindness implies this could be my son, my mother. This is clear in the following appreciation of the coroner, noted by a father who was otherwise met with very little kindness:

She said my decision will be based on what I've heard. It's either going to be death by addiction to drugs or accidental death. And she said I think on the balance of probability it really is accidental death and she just looked at me and said, 'Is that okay?' and I said, 'Yes', and she said, 'Okay', which was very nice. And she's fine. She was on my side. (E4a)

We should note that coronial kindness over the verdict is not entirely unproblematic. It may bias death certification; and a kind coroner who avoids a suicide verdict may perplex witnesses who discovered the body.

Feeling with, feeling against

Compassion literally means 'feeling with'. Stigma, by contrast, entails disgust at the other – feeling against. Labelling, stereotyping and separating us from them are cognitive judgements, but they are also inherently emotional judgements communicated through feeling. Thus, in this mother's quote, cognitive judgement (just 'another junkie') and emotional disgust ('clearly didn't like him') are connected:

The police were very much of the opinion that this was yet another junkie. Clearly didn't like him because he had a history. (S4)

A mother and father spoke about the inquest:

But the PC who dealt with it ... he wouldn't face us. He wouldn't talk to us ... He didn't come to speak to us. (E29a)

By contrast, a respondent commented on the unexpected positive ambience in the hospital mortuary:

I thought well it's going to be very clinical, I think you watch too many detective movies. It wasn't like that at all ... He was lying and he looked serene ... with lighted candles ... A little bit of ceremony ... I was glad they did that. (Father, E6a)

Doing your job

We have contrasted the labelling, stereotyping and separation entailed in stigma, with the individualising and sense of kinship entailed in kindness, but both stigma and kindness entail feeling. Yet there is something else our participants reported that is feelingless, unemotional: practitioners and officials who do their job competently and efficiently, but coldly, without feeling. That can hurt as much as explicit stigma. However, medically efficient the Accident and Emergency staff,

I did feel desperately let down because ... there was a young man fighting for his life and surely somebody in that A&E department would have had the decency to say, 'Well I think he needs next of kin' but no, they didn't. (Mother, E14b)

Police could also be reported as cold:

It was horrible, so cold, they don't make it, 'Oh I'm sorry but I've got to tell you this news', it's 'Aye, we identified her'. (Mother, S2)

And concerning the procurator fiscal:

I thought there is no emotion with you – no compassion and empathy – it was just a job. (Mother, S17)

By contrast, professionalism and efficiency were welcomed when done with consideration and care. Thus, a policeman was commended for mentally registering there had been a marital separation and enquiring who therefore would be organising the funeral and be the police's main contact. Tact could also be noticed and appreciated:

So he was put in a difficult position, but he did it very tactfully and was very sympathetic. (Daughter, E20b)

Care in announcing the death was appreciated by this mother:

I let the two guys (paramedics) in and one went over to see Johnny and the other one was standing with me and I was crying and I just thought he'd just collapsed and everything was alright. And it was the way that one was on his knees and he looked at his mate and he said: 'Could we go through to your sitting room Mrs Campbell. What is your first name? Is it Mary?' and I said: 'Yes, sure', and they sat

me down and then after a couple of minutes the other fella came through and he just looked at his mate and I knew right away. He came over, knelt down and said 'This is Mary' to his mate. And he says: 'Mary', he says, 'I am sorry but Johnny has passed away' ... They were so nice, they had been so nice. (S5)

This may be contrasted with interviewees who told of ambulance crews criticising them for calling them out to someone who clearly had been dead for some hours.

These findings are summarised in Table 2. What distinguishes kindness from stigma is identification with the sufferer, a sense that 'I could some day find myself in their shoes'; this identification, or lack of it, is felt as much as cognised. This raises questions about professional competence: does professionalism require no feeling, no identification? In the experiences we report, the answer is clear: professionalism without any feeling or identification amounts to a lack of compassion, and compounds the bereaved person's shock and grief.

Bereaved families value not just professional competence but *how* competence is executed – with kindness or sympathy, judging the person as one of us, deserving support; or as someone outwith respectable community and undeserving of support. This has roots in a historic divide in Britain between the deserving and undeserving poor. How practitioners respond to those grieving a substance-using family member compares with how they respond to mental health problems or to an incontinent patient with dementia: 'This could be me/my son/my mother'. Or 'I'm disgusted. I can't bear to think this could be my family'. Professional detachment may defend against either identification or disgust, so is functional for the practitioner, but for our interviewees worsened an already bad experience.

Discussion

We have shown both stigma and kindness to contain cognitive and emotional components. We now reflect

Table 2 Practitioner orientations

Practitioner orientations	Emotions and cognitions	
	Feeling	Identification ('This could be me')
'Just a job'	Absent	Neutral
Professional distance	Absent	Neutral
Kindness	Present	+ve (identification)
Stigma	Present	-ve (disgust)

further on cognitions and emotions, drawing on theories from death studies, psychology and sociology, to identify some barriers to kindness, how to promote kindness and some unanswered questions.

Cognitive labour

Death a time of judgement

It is normal for humans to make judgements of self and others. At no time in the life course are we more prone to make judgements than at the end of life. Elderly people may conduct a life review (Butler 1963), falling mountaineers and others who have a few seconds before they miraculously survive report their life flashing in front of them (Kellehear 2014), religions have portrayed death as a time of judgement, and eulogies assess the value of the deceased's life to those who survive them. Thus, judgements are made in the light of one's own impending death and about those who have died, while mourners judge themselves by the deceased's life and values. Such judgements, however, are usually based less on assumptions and stereotypes than on personal judgement of a unique life.

It is unrealistic to ask practitioners encountering people bereaved after substance use not to make judgements. However, unlike family members or funeral eulogists, practitioners such as emergency medics, ambulance crew or police have little time or knowledge to make an informed judgement about this particular person or their family. Judgements will inevitably be broadbrush, and assumptions and stereotypes difficult to avoid. What our interviewees ask is simply that such judgements be judgements of kinship, not of othering.

Meaning-making

Psychologist Robert Neimeyer has researched in detail how mourners strive to create meaning in the face of loss. Meaning-making is critical after traumatic deaths (Neimeyer & Sands 2011, Zandvoort 2012) which disturb mourners' sense of the order of things (Guy & Holloway 2007); struggling to find meaning in the death can predict complicated grief and a poor bereavement outcome (Davis *et al.* 2000). Not only mourners but also practitioners need to make sense of the traumatic deaths they encounter, though this has barely been researched. We know that a person can feel supported or disturbed by the meaning their own family gives to a death (Nadeau 1998), but they can also feel supported or disturbed by practitioners' meaning-making. We have data showing how coroners and their staff can help families understand the death and the life that led to it;

how treatment agencies' framing of substance dependency as a disease can ease a family's guilt; how the stereotyped meanings some police give to drug deaths can deeply disturb families; how families try, and often fail, to influence the meanings that media give to the death. All this entails cognitive labour.

Emotional labour

Feeling rules

For practitioners to root instant judgements in kinship also requires emotional labour. Msiska *et al.* (2014) summarise two kinds of emotional labour required of healthcare workers as they work with patients; workers need to repress emotions such as disgust or frustration, and to detach from instinctive identification (Mann 2005). Being kind to someone who repels you entails emotional labour, as does not being incapacitated by sadness at the misfortune of somebody with whom you identify. It is the first of these which concerns us here. Choosing to see the bereaved person not as an alien but as someone like me causes me to feel a degree of pain; it goes beyond professional distance, and arguably could lead to burnout. What our interviewees value, however, is not total embrace by the practitioner or hours of their time, but simple acts of kindness. Informing somebody that their son has died takes much the same time whether done with kindness or with indifference. The question is whether such kindness might lead not to burnout but, as Youngson (2010) has argued, to greater job satisfaction?

Others see this in terms not of job satisfaction, but of exploitation. Bolton and Wibberley (2014) analyse the labour required of those who provide homecare to frail elderly people; as well as their formally contracted labour, they also find themselves engaging informally in emotional labour that, though highly skilled, is not contractually recognised (England & Dyck 2011). Are our participants asking a whole range of practitioners to add unpaid, unrecognised emotional labour to their already harsh workloads? Care workers are paid to care, but care is not at the heart of the contracted labour of journalists, coroners and police officers – though as noted above, a little goes a long way.

Display rules

Though emotional distance in the face of others' pain is an individual response, it is influenced by group norms (Ballatt & Campling 2011), not least when a practitioner group is repeatedly exposed to human misery and the terrible consequences of human error. Stoical norms, including black humour (Young 1995),

are likely to prevail among practitioner groups which encounter frequent death, especially sudden, untimely or violent death – norms which may conflict with the more expressive norms that have become increasingly influential among western publics who now encounter death rarely (Walter 1999). Our bereaved interviewees are *not* asking practitioners who frequently work with traumatic deaths to be tremendously expressive or revealing of themselves; but our interviewees do tell us that small kindnesses can greatly help. The sympathetic ambulance crew, like the soldier writing to his deceased comrade's family, understands that their occupational group's necessary stoicism need not preclude small kindnesses to a bereaved family. Emphasising the virtues of tact, courtesy and kindness may sound simplistic, but it is what our interviewees emphasised time and again.

Education

If our interviewees have a take-home message for practitioners, it is this: regardless of your job, never forget you are a human being dealing with another human being who is bereaved. Several educational campaigns – all initiated by people bereaved by drugs or alcohol – aim to drive home precisely this message. Significantly, they understand that education must work at an emotional level if pre-cognitive assumptions are to change. DrugFam, an organisation aiming to build support for people bereaved by drugs and alcohol, promotes the play *Mum, Can You Lend Me Twenty Quid?*, depicting the experience of DrugFam's middle-class founder as she struggled with her son's addiction to heroin and eventual death (Burton-Phillips 2008); the play has been performed numerous times, not least to police officers, prisoners and prison staff. One testimonial in the play's advertising material from a police commander states:

As a father to two wonderful children, I found myself constantly asking how I would have felt if it were me. With 29 years' service as a police officer behind me I have witnessed an awful lot of unenviable things in life. Yet, the play had as profound an effect as any such experiences...

Such testimonials show how the play works to de-other and to evoke empathy, seducing even hardened professionals to see and feel that this could be their family. It understands how stigma operates, and what is needed to counter it.

A similar educational strategy challenging stereotypes is to depict the deceased's humanity and how he or she was loved. In a recent Alcohol Concern

video, three young people talk about each of their alcoholic parents who, despite their drinking, were profoundly loved. The same message comes from a mother's biography of her son who died from heroin (Skinner 2012). An Israeli site challenging the stigmatising of those grieving a suicide depicts several suicides, each with a photograph of the person looking well and happy. [*B'shoil Ha'haim* (Path to Life).] The message is the same: the deceased was not just an alcoholic, a drug addict, someone who took their own life; they were essentially good, fun, caring human beings who loved and were loved, and are therefore worth grieving.

This strategy of course purveys its own stereotype. Though in our sample, almost every parent we interviewed loved their deceased child, not every adult child loved their deceased parent, while others loved them ambivalently. Not all may feel positive about propaganda depicting all those who die through alcohol or drugs as loved and worth grieving.

Conclusion

Stigma relies on labels, stereotypes and othering; for those mourning a loss due to alcohol or drugs, they may further complicate an already difficult grief. However, stigma can be challenged through small kindnesses even from busy professionals encountering those whom society considers undeserving, and through educational campaigns that recognise stigma's emotional and cognitive dimensions. Though there will be differences of detail, much of what our interviewees said is likely also to be true after other stigmatised deaths such as suicide, mental health problems or AIDS (Guy & Holloway 2007, Holloway 2007). More widely still, our argument contributes to current debates about how to foster compassion in healthcare and other public services. We fully acknowledge the structural forces that limit big kindnesses; nevertheless, our interviewees reveal the redemptive power of small kindnesses. In their experience, a little can indeed go a long way.

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