Experiences of unpaid carers of engaging with mental health services in Edinburgh





Report of consultations with unpaid carers caring for a person with a mental health condition

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1. INTRODUCTION

This report summarises findings from consultation activities undertaken with unpaid carers caring for a person using mental health services in Edinburgh. The research focused on carers' experiences of shaping the care of those they cared for, and how well supported they felt as carers. The work was conducted as part of a Thrive funded project delivered by VOCAL Edinburgh which started in December 2020.

2. CONTEXT

The project was started during the COVID pandemic, with a national lockdown occurring a month in. This posed considerable challenges for the carer engagement officer leading the project, with negative impacts on promotion and carer engagement.



In addition, as this project started, other Thrive funded projects were also implementing their services. The new Thrive model in Edinburgh offers a re-imagined approach to supporting mental health of its citizens and involves considerable service redesign work within and across agencies. As a result, the findings in this survey may reflect 'pre-Thrive' practices and service delivery models.

The findings can therefore usefully contribute to baseline data obtained as Thrive is implemented across the city. Hopefully, any current and future improvements in carer support and involvement in mental health services arising through the Thrive transformation will present a changed picture in the coming years.

3. METHODOLOGY

A range of quantitative and qualitative approaches were used to gather carer feedback, enabling carers to express themselves as they wished. Data was gathered through a survey, two focus groups, one-to-one interviews, storytelling sessions and other documents such as emails and letters. The data gathering stage took place between June - September 2021.

The survey was distributed and promoted online, so it is unclear how many people were reached in total. There were 34 respondents (33 online; 1 paper) to the survey. Six carers participated in the two focus groups. 14 carers also took part in a one-to-one session. Several paper-based submissions were also received, mostly in email format. As only a small number of respondents participated in the survey, findings should be read with caution, however, it should be noted the supplementary information from the qualitative research supports the survey findings. Thematic analysis of the qualitative data was conducted.

Despite the challenges highlighted above, the officer was able to obtain the views of 70 carers. The report seeks to give a voice to carers who are quoted heavily within the report. All names have been changed to protect identity. Similarly, no individual service is highlighted. Carer feedback is therefore generalised when discussing services and professionals.



4. FINDINGS

Most carers (68%) had been in a caring role for more than three years, with over half caring for longer than five years (54%). Many respondents were parent carers (42%), with twice as many caring for an adult child compared to a child under 18 years. Thereafter, siblings (12%) and spouse/partner (5%) were the most common carer relationship categories. Respondents reported using services across the city including those in the voluntary sector and Edinburgh Health and Social Care Partnership. Some mentioned they had only used one service; others used three or four. Some private provision was being utilised. However, it should be stated the report does not highlight any particular service, as analysis by specific providers was not undertaken.

Four main themes were found from the data:

- CHALLENGING CIRCUMSTANCES OF CARERS
- POOR ATTITUDES AND ACCOUNTABILITY OF PROFESSIONALS
- LACK OF CARER RECOGNITION AND INVOLVEMENT
- THE POWER OF GOOD SUPPORT AND ENGAGEMENT

These themes are summarised here and described in more detail in the following sections.

CHALLENGING CIRCUMSTANCES OF CARERS

This category includes various challenges faced by carers, often for several years, and its impact. Carers can sometimes lack confidence knowing how to provide appropriate care to the person they supported and can operate with high levels of risk. This is clearly illustrated by Worthington, Rooney, and Hannan, 2013:

This theme also captures the reported lack of information and signposting to carer support by professionals carers were in contact with, and their associated feelings.



If carers are not included and treated as partners this can have a severe effect on the service user's condition, the carer's confidence in services and the professional's ability to support their client adequately.



POOR ATTITUDES AND ACCOUNTABILITY **OF PROFESSIONALS**

This section covers a range of professional issues, including a perception that services and/or professionals could 'pass the buck' to avoid taking responsibility, a lack of empathy towards carers and poor attitudes of some professionals leaving carers feeling ignored or made to feel like a nuisance.

LACK OF CARER RECOGNITION AND INVOLVEMENT

This theme reflects the lack of perceived value professionals have of carers, that their caring role is frequently underestimated by professionals. As a consequence, time was not invested in carers to support them in their own right or assist them in shaping care for the person with a mental health condition. This led to an initial lack of assessment and support for carers, often over years, leading to poor carer outcomes.





THE POWER OF GOOD SUPPORT AND ENGAGEMENT

A less pronounced theme was that of the value of positive carer support and engagement, with some carers feeling fortunate at having had good experiences with professionals and teams. However, this seemed dependent on individual professional commitment rather than as a result of robust systems, processes and practices.

4.1 Challenging circumstances of carers

Almost all carers responding to the research reported some type of challenge(s) faced whilst being a carer for a person with a mental health condition. This theme contains two main dimensions, firstly the challenges associated with the caring role and secondly, the challenges associated with being referred to carer support services.

A key factor for carers was their perceived ability to provide effective care for the person with a mental health condition. Whilst 22 respondents felt confident in understanding and managing risks associated with the condition of the person requiring care, more than double that did not (45 respondents). 30 respondents specifically reported they needed further support than was currently available to them. Although survey respondents were low in number which may impact on findings, 86% of survey respondents felt they had never or only sometimes, been given sufficient information and support to manage risk. 57% reported that they needed more support in this area.

Managing risks associated with suicidal ideation was singled out by several carers as an area of considerable difficulty with a lack of perceived support unless the situation was urgent:

person requiring care:

Feeling the person has to have actively completed the act [suicide] before they are eligible for their service and therefore no point in contacting them.



There is seldom one sufferer, when loved ones are struggling to keep severely anxious or depressed people from making wrong choices or maybe suicide.

It was not uncommon for carers to talk about the impact of caring on their own mental health, with some noting their role left them needing support in their own right. The cause of mental health distress amongst carers was sometimes attributed to a lack of suitable services for the

It has been a very tough ten years. The frustration that Neil has had and my other son... dealing with all of this, feeling I had to fill the gaps that services were not proving or providing inadequately. Feeling frustrated for my sons took its toll on me.



Many carers reported struggling to identify as a carer and be referred for carer support. Some talked about how their awareness of becoming a carer emerged gradually:

I think I probably didn't identify as a carer because she was my daughter...I just saw it as part of parenthood. It seemed different from when I was caring for my mother... It's only recently that I have identified myself as a carer for my daughter.



That whole mental health world was very alien to me – so psychiatric hospitals and words like 'schizophrenia' were not part of my vocabulary and certainly I didn't expect to identify myself more and more as a carer.



89% of respondents rated the carer related support and information they received as being 5 or less on a 10-point scale with 10 being excellent, indicating that most felt support and information could be improved.



Less than half of all respondents (43%) reported being signposted to carer support, and often this had taken a long time to achieve:



I have only recently been informed of a support service for carers even though I have been caring for a person with a mental health condition for a number of years.



It's only in this last year when things have been so critical with Jenny that social work staff have said to me 'why don't you get in touch with Care for Carers.' They were just fab.



In summary, despite the complexities of caring for a person with a mental health condition, and the resultant impact on carers, carers did not feel professionals took their situation into account and this may account lack of referral for carer support.

4.2 Poor attitudes and accountability of professionals

The theme of professionals not taking responsibility to identify and support carers, and a lack of flexible approaches to ensure they are treated as equal partners in the delivery of care, was identified by over half of respondents, 52% who reported experiencing negative attitudes from mental health professionals. There was a sense of distance from mental health professionals amongst carers, and of feeling judged, abandoned or ignored by them:

My feeling (is) of being a stranger to the services.

They know their loved one better than any health professional, yet they are ignored, patronised or placated with no good results for the sufferer.

I have to say the only people who showed empathy were the two paramedics...They didn't make me feel that it had nothing to do with me, but the other people did. Their whole manner. I've never cried so many tears in my life.



Issues relating to discharge arrangements were mentioned by some carers, who felt improvements could be made to ease the transition between hospital and community:

When people breakdown and go into hospital...then when they are reasonably settled and well enough there, they are not actually equipped enough to cope in the world that stressed them out in the first place, and they go right back to the world. So, it's the crossover - people come in, in a hurry, but should go out slowly. There should be come crossover of life outside the hospital while they are still in hospital to help them to make that adjustment because it's an almighty shock for them.

They treat the ill person and send them on their way. Ironically...they look at discharge in a physical sense, any additional support required, but do not think about how the loved one is to adapt/cope with managing a person with mental health issues in their household.

Aligned to the sense of distance and fragmentation between home and hospital was a sense that professionals and agencies did not take responsibility and/or would 'pass the buck':

Demand for services appears to be so high and resulting defensiveness of service providers so entrenched that they no longer fulfil their stated brief.

This led to strong feelings amongst carers:

Exasperated. Desperate. Completely unsupported. I am infuriated at the lack of clarity on how to access services or what you can expect them to provide and putting all responsibility back on to informal carers and seriously ill individuals.



There is NO accountability, and the usual 'lessons will be learned' message is empty and pitiless to families concerned. The state of care at present for mental health sufferers and their carers is basically scandalous.

Over two thirds of respondents (67%) reported they had not been informed of how to complain or compliment the service being used.

4.3 Lack of carer recognition and involvement

This theme has already been mentioned above, and the most comments received related to a lack of care involvement in care planning and decision making. Nearly two thirds of these comments reflected that carers were not offered opportunities to discuss the care, treatment and recovery of the person they cared for.

Possible reasons were offered by carers in response to this lack of engagement by mental health professionals, including confidentiality, the person with a mental health condition being the primary focus and a lack of awareness regarding carer needs:



I didn't really know enough about what I was supposed to do, I didn't really understand enough about what was wrong. But the difficulty was patient confidentiality.

There needs to be a balance between confidentiality with the client but also a duty of carer to take into account the needs of the family. Bring back compassion and humanity and look at how carer information is impacted by data protection.



Several carers highlighted the need for a cultural transformation and a holistic, family-based approach within mental health services:

Change the culture in services – work out a way we can all contribute; people should feel welcomed into services as they are in the third sector.





Given many carers are new to the mental health world at the stage of diagnosis, carers would welcome better information and support to enable them to care more effectively:

I realise some situations are difficult to foresee but if I could have some idea of what to expect for Safia over the next few years or so, with appropriate advice, I can prepare myself, in advance, to be able to give her the best support that it is possible for me to provide. Presently, I feel I am moving through a tunnel with a mask on, not able to see which way to go or avoid obstacles.

Becoming effectively involved in decision making was further compounded for working carers, who found the system inaccessible as it did not take into account the fact they were working:

I appreciate it's not easy for the NHS, but the current system assumes that you have all the time in the world - that you have three hours to wait to see somebody for an appointment and the difficulty for working carers is that they are rushing from A to B. Because if they are not working, they are supporting somebody and if they are not doing that they are working.



4.4 The power of good support and engagement

Although positive comments from carers regarding their experiences of engaging with mental health services were less frequently received than negative views, the difference that receiving good support from mental health professionals was noted amongst some respondents. Positive feedback appeared to relate to specific professionals or teams, rather than the wider system.

Some carers who had positive experiences with specific teams or individuals appeared conscious these were not universal and felt an element of luck had befallen them:

It was hard though, to often be told what was happening, not asked, although I am aware that I was fortunate that even this happened due to the patient's lack of ability to consent and that I supported the decisions made.



I am really lucky with his psychiatrist...I can phone her up if I am worried about him.



Carers appreciated it when professionals took the time to speak to them, to allow them space to ask questions and be referred for carer support:



It was really helpful to be offered a one-off carer's appointment to give me a chance to talk to a staff member on my own about what was happening and for them to signpost me to services such as VOCAL.







The third sector, in particular carer support services, received praise from those who had benefited:



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However, the third sector was reported as being overly complex to navigate by one carer:

Carers were given an opportunity to say what they think would help, either now or in the future. Overwhelmingly, carers (90%) wished to be treated with respect, compassion and honesty as well as being involved as equal partners in care:



Listens to the carer, addresses problems in a professional way and recognises that carers are part of the support.

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Carers would like professionals to be more aware of the impact their attitudes and systems can have, and the fact these can be experienced as daunting, distressing and scary:

-66

Everything in this story matters, the whole thing was unequal from the minute she got in that ambulance, from when staff came to the house, to me it was all awful, and every stage of her illness was awful.



Child Protection meetings should be totally looked at as people are terrified of them, there is no need for this, I'm aware how serious situations can be, but there is no need for them to be so terrifying.





This involved improved communication between service staff and carers/families, including feeling validated and heard:



One that listens and responds to concerns raised, that works together with the carer and realises the carer is an important member of the support team who has useful information about the person being cared for.



[That] they talk with me respectfully and listen to my views...[That] they are happy to include me in discussions about care when my friends has given consent for this and will take my thoughts into consideration when reviewing the care plan.



As part of this, carers felt professionals should understand and value the role that carers play in supporting the person with a mental health condition:



Respectful. Professionals that seem to work alongside carers.



Don't ignore close family or carers who really know they person for any length of time...They know the behaviors of the person, the triggers of the person, what stresses them... We all have this moveable thing stress. Close carers know what that is for the person they care for and this should be built into care plans





There was a clear call from carers for professionals to pay closer attention to the need to obtain information from carers, as well as to provide them with more information to enable them to care more effectively:

I would have liked someone to have spoken to the whole family, to make things more clear. Someone to explain things better, more support for me. It would've helped us all understand it better.'

A further consideration raised by carers was the need to be involved and identified as a carer at the earliest possible opportunity:

Improved coordination and communication between services was also an area highlighted by carers as an area for improvement:

I did not really know enough about what I was supposed to do. I didn't really understand enough about what was wrong.

I think getting some help at the time quite bluntly. I mean whenever the help arrives its welcome, but it needs to be timely.

(We need) More staff people talking to each other between services. I know there has to be confidentiality but the services need to know what's going on with each other. I'd like for every service to be open and working with each other.



This would also prevent carers having to keep repeating information:



So, I want them to listen to carers and minute their meetings. You might have a very helpful supportive conversation with a mental health professional, and they say good we will take that into account...I have had that conversation with lots of people, but nobody writes it down, so it just dies. When you have meetings to discuss care plans write these things down and share it - I don't know why they don't.



Several carers described how they would like to see an integrated service working. Some talked about what this might look like:



More staff talking to each other between services...I'd like for every service to be open and working with each other. Do they need to be named separate services? Could we not have something like a Hub where folk can access all the services they need?



All organisations involved in the care of a person should be interconnected and aware of each other.







5. DISCUSSION

These findings highlight views from carers for a person with a mental health condition living in Edinburgh. As most of the carers participating were self-selecting, in that they chose to become engaged with the research, the authors do not claim these results are representative of all carers. However, the views expressed by respondents are quite concerning and speak of a system that needs to change and find ways of better engaging with carers.

The following discussion will focus on two key dimensions of carer engagement. Firstly, the need to provide supports to carers to enable them to continue in their caring role and secondly, the need to recognise the important role carers play in delivering care and how professionals can support this.

5.1 Rights based approach - carer rights

The Carers (Scotland) Act 2016 was introduced to provide better and more consistent support for carers and young carers so they can continue to care, if they so wish, in better health and to have a life alongside caring. The Act introduced duties to provide support for carers who meet local eligibility criteria, to offer carers an Adult Carer Support Plan or Young Carers Statement, to set up and maintain an information and advice service for carers and to inform carers and invite their views prior to the discharge from hospital and take these views into account before the discharge occurs.

Further, the Mental Health (Care and Treatment) (Scotland) Act 2003, states the rights and views of carers must be taken into consideration as much as possible when any decisions about the care and treatment of the person requiring care are taken. Carers should be provided with information they need to provide effective care but should not receive information the service user does not want to share.

The Carers (Scotland) Act 2016 is still being implemented in Edinburgh and likely reflects the lack of reference by carers, to key aspects of the legislation such as Adult Carer Support Plans. However, the Mental Health Act has been enacted for over 15 years now, yet the requirements for carer engagement did not appear to have been upheld for most carers involved in the research, even in cases where consent to share information had been provided.

The experiences of carers involved in the research were frequently of marginalization, exclusion and neglect by mental health services. Where positive experiences of dealing with professionals were reported, these seemed dependent on an individual or team, rather than across the board. Carers could only speculate on why mental health professionals did not engage them well but were clear about the impact this had on themselves as carers and as individuals in their own right. These findings are not specific to carers living in Edinburgh and indeed, a thematic report published by the Care Quality Commission in 2015 of mental health providers in England also reported widespread evidence of people not being treated with empathy during a mental health crisis, with carers struggling to feel heard and supported (Care Quality Commission, 2015).

The recent proposals for a national care service for Scotland emphasise the need to adopt rights based approaches when supporting people and sought views on whether to extend rights for carers, including the right to a receive a break from caring. VOCAL and Thrive Edinburgh would like to see a strengthening of carer rights, including the ability to seek redress where rights are not met. Carers perform a role akin to paid carers, yet their needs – to maintain health and wellbeing, achieve a life alongside caring and receive sufficient information and support to enable them to undertake their role - can often be overlooked by the very professionals whose role it is to empower and support them.

5.2 Identifying carers and referring for support at earliest opportunity

Carers generally do not choose to become carers. More commonly they adopt the role following the diagnosis of someone close to them, such as a relative, partner, friend or neighbour. As a result, many find the world in which they find themselves, complex and daunting to navigate. Many will want to know more about the medical condition of the person they care for including medication, treatments and services and systems they are likely to encounter.

Caring for someone with mental illness can put a strain on personal goals, health and wellbeing and relationships, particularly when living in the same household or in frequent contact. VOCAL's Carer Survey undertaken in 2021 found almost four out of five carers (79%) agreed with the statement 'Being a carer has affected my mental health', with 40% strongly agreeing. Shah, Wadoo and Latoo (2010) summarise the objective and subjective impacts such a caring role can have:



Objective burden relates to the practical problems experienced by relatives such as the disruption of family relationships, constraints in social, leisure and work activities, financial difficulties and negative impact on their own physical health. Subjective burden describes the psychological reactions which relatives experience, e.g. a feeling of loss, sadness, anxiety and embarrassment in social situations, and the frustration caused by changing relationships. Grief may also be involved...[and] can lead to unconscious hostility and anger.



Carers can gain deeper understanding and be more supportive to the person they care for, when equipped with knowledge about the condition and how it can be managed. This research revealed carers were keen to gain more information and become more competent as carers, as they acknowledged the critical support role they played. Good support from carers has been found to strengthen mental health recovery (Lauzier-Jobin and Houle, 2021). Further, carers feel increased confidence and more in control of their lives when they are well informed, generating positive personal outcomes for carers in their own right.



However, the research illustrated many carers did not feel, or had not felt in the past, sufficiently knowledgeable about information and support available to them. There was a call from carers for professionals to take time to speak to them, to identify them as carers at the earliest possible opportunity and make sure they could access carer information and support.

Current policy objectives argue carers should be supported to maintain a life alongside caring and carers should not be expected to care more than they feel able to or are willing to. If carer health and wellbeing is not addressed, there is a risk the caring relationship might break down or the carer choses to stop providing care. There is not only a moral imperative to support carers, but also a financial one - replacement care might need to be sourced should the carer stop providing it, or indeed, the carer may end up also requiring care themselves as been evidenced with some involved in this research.



5.3 Better engagement as equal partners in shaping and delivering care

It was argued above that carers need support, not only in respect of their own personal wellbeing, but also in order to provide effective care for the person with mental illness. All carers spoke of areas they would like improved in relation to their ability to shape care for the person they cared for. Transitional stages were highlighted by some, for instance, improved transition support between children and adult services. Another key transition area singled out for improvements in carer support was between home and hospital. The Carer (Scotland) Act 2016 introduced a right for carers to be involved in discharge planning arrangements for those leaving hospital. In this way, it builds upon and strengthens the rights of carers to become involved in decision making embedded in the Mental Health (Care and Treatment) (Scotland) Act 2003.

Carers provided insights into their difficulties at both admission and discharge stages, with carers left managing high levels of risk such as feeling required to assess a person's suicidal state prior to contacting mental health services or feeling responsible for providing an adequate level of care at the point of discharge. Carers reported a gulf in levels of support between hospital and community and found it impossible to recreate the degree of safety or support hospitals could. They recognised their own limitations and argued for higher levels of support for the person requiring care immediately upon leaving hospital. The barriers created by confidentiality were noted by some carers who also believed more could be done to overcome these barriers to ensure effective support for themselves and the person they cared for.

In Edinburgh, the Health and Social Care Partnership provide a carer support service for those caring for someone in hospital and can help carers become involved in discharge planning. However, this service does not currently cover the Royal Hospital for Edinburgh, although carers did report pockets of good practice in particular areas of the hospital. Whilst the Edinburgh Carers Council can provide support to carers of those with mental illness, this is specific to advocacy support. However, there are a wealth of community-based carer support services available to support carers at all stages of their caring journey, discussed in the next section.

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5.4 Integrated service delivery

At the end of 2020, comprehensive community based mental health services were commissioned by the Edinburgh Health and Social Care Partnership to offer a continuum of mental health support for people living in Edinburgh. These collectively are known as the 'Thrive collaborative'. As this research was conducted during 2021, it is likely that the carer experiences reflected the previous arrangements as the refreshed approach was still emergent. It is unclear whether and how this collaborative will impact carer engagement in the future. Although third sector support generally received positive feedback from carers, at least one commented that the complex range of offerings added to the confusion about what support was available for carers.

One theme arising from the findings of the study found carers would value further integration of services. For instance, several carers spoke of their desire for a 'one stop shop' approach to the delivery of mental health support that should include support for carers. Ideally this should be provided at times suitable for carers, including out of hours support for working carers or for those dealing with a crisis. Other carers described the need for more effective joint working at team level, where carers are seen as a key team member, rather than observing from the sidelines as was their current experience. Good carer support should not be perceived as being opportunistic or serendipitous, dependent on the goodwill of practitioners to inform or support carers. Rather, the intention to identify and refer carers to carer support services should be embedded within systems, policies and procedures so carers are routinely identified and offered support.

In tandem with changes to community based mental health services across Edinburgh, extensive new carer support contracts were also awarded to third sector organisations, with these contracts commencing at the start of 2021. There is a significant range of carer support now available across Edinburgh, particularly amongst the third sector, and professionals should not be expected to be able to replicate this in their own practice. Rather, professionals could usefully identify and refer carers to specialist carer support services across the city.

6. CONCLUSION

This study of carers' experiences of mental health services in Edinburgh suggests considerable improvements could be made to ensure carers are supported and equipped with the information and skills required to provide care as an equal partner. Whilst it is understandable that the primary focus of mental health practitioners is on the person requiring care, this does not mean that carers' issues and needs can be neglected. A preventative approach that offers early support for carers, will reap dividends in the mental health recovery of the person requiring care. Over time, by supporting carers more effectively, the degree and frequency of mental health distress exhibited by the person requiring care is likely to reduce. Offering holistic support to those providing informal support will therefore generate considerable long-term gains for mental health services.

Many of the suggestions for improvements from carers are not complex, time-consuming nor expensive. Rather they speak of the need for a systemic change in the way professionals perceive carer involvement and engagement, of more inclusive and empathic attitudes and a recognition of their role as equal partners. More training for professionals, with support for managers in changing policies and practices, will likely improve carer experiences in future. Professionals should acknowledge their responsibilities for ensuring carers receive adequate information and support and take the time necessary to work alongside carers.

There should be greater accountability across service boundaries, so people do not feel passed from pillar to post. There is a sense amongst carers at present that what happens in the community is not the responsibility of hospital staff, yet this simply compounds a 'revolving door' approach where re-admissions are likely and indeed, only a matter of time. Hospital staff should work more intensively with patients and carers to prepare them for life in the community and be willing to engage with community-based staff.

This research report represents the outputs of research undertaken during the first year of both Thrive and carer contracts. It was deliberately broad in this first instance, and future research produced as part of the project will likely be more nuanced in terms of issues and services covered. The authors hope that the findings will provide baseline information on the current state of carer engagement within mental health provision in Edinburgh. They also very much hope that the new Thrive collaborative and extensive range of carer support now being delivered across Edinburgh will begin to make a difference in terms of the ability of carers to receive the support so clearly needed by many. However, this is very much dependent on the willingness of services to recognise the value of carer support and to identify and connect carers to support, as well as to find ways of involving them in shaping care for the person with mental illness. National government have provided considerable financial support to support carers in light of the introduction of the Carers (Scotland) Act 2016, but in order for this to make a difference, local practitioners must be aware of how to connect carers to this support and be willing to treat them with respect and dignity to avoid further marginalization and isolation.

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