

CLINICAL PAPER

The elephant in the room: the impact of bowel dysfunction on people with multiple sclerosis

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Abstract

The aim of this study was to investigate the relationship between constipation and the quality of life (QoL) of people with multiple sclerosis (MS). Using a phenomenological approach, in-depth interviews were undertaken with 12 people who had a diagnosis of MS and also suffered from constipation. Themes were derived from inductive analysis of verbatim transcripts of the interviews. The participants framed their observations regarding the impact of constipation with one core theme: spoiled normal identity, brought about by the reactions of others, culminating in a sense of social stigma. The main strands of the interviews were the associated issues of aesthetics, decreased self-esteem and loss of control. It was also evident that the impact of this condition on everyday life was significant. This was confounded by embarrassment, and the reluctance of patients and clinicians to talk about the problems pertaining to a sense of isolation. Furthermore, inconsistent advice and information often led to self-management by trial and error, which sometimes had disastrous consequences. From these interviews, it would appear that constipation affects the QoL of some people with MS, restricting their activities, and making them feel isolated and out of control. Multidisciplinary team input is vital for the effective management of clients with MS and bowel dysfunction, and there is a specific need for the symptom of constipation to be more openly discussed and strategies for relief identified. Further research into the impact and treatment of all bowel problems in people with MS is required.

Keywords: bowel dysfunction, constipation, multiple sclerosis, quality of life, stigma.

Introduction

Multiple sclerosis (MS) is a demyelinating disease of the central nervous system and is the most common neurological disease affecting

young adults (Compston & Coles 2002). Currently, there is no cure for this condition, but life expectancy is not reduced, and therefore, people with MS live with and manage their symptoms for life (Kesselring & Beer 2005).

Constipation is relatively common within the general population and its incidence increases with age (Kamm 2003). Because of the lack of a

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clear definition and an unwillingness to seek help, estimates of its prevalence vary, but it is thought that 20% of older people living in the community suffer from this problem (Petticrew *et al.* 1997). The associated symptoms often have a significant impact on quality of life (QoL), and can range from headache and fatigue to feelings of bloatedness, loss of appetite, nausea and vomiting (Glia & Lindberg 1997). In a study that recruited 74 participants with MS and bladder dysfunction, constipation was reported by 67% ($n=50$), 36% ($n=27$) had experienced faecal incontinence (FI) and 25% ($n=19$) had suffered from both (McClurg *et al.* 2008). These figures are similar to those reported by Nortvedt *et al.* (2007), whose study of 56 participants with MS found that 45% had FI and 69% had constipation. The causes of the increased levels of constipation in people with MS are multifactorial, and include poor diet, lack of exercise and the side effects of medication. It is also thought that the disease process itself may lead to a “slow transit bowel” or pelvic floor dyssynergia (Fowler 1997). Moreover, it has been reported that people with MS have between two and three times as many admissions to hospital as the non-neurological population for impaction, megacolon, constipation and volvulus (Sonnenberg *et al.* 1994).

Despite evidence that bladder and bowel problems are often considered to be the most distressing issues associated with MS (DasGupta & Fowler 2003), and are rated on a par with mobility problems (Norton & Chelvanayagam 2010), there has been remarkably little research relating to either the management of bowel dysfunction or its impact on QoL in people who have the disease. A recent report on an online survey completed by 155 members of the MS Society concluded that some people with MS experience bowel dysfunction that has a significant impact on their QoL, that further research is needed to evaluate the effectiveness of interventions and that many patients feel reluctant to discuss their bowel problems with healthcare professionals (HCPs) (Norton & Chelvanayagam 2010). The results of this survey complement an earlier Cochrane Review that could not make any recommendations about management because of a lack of evidence (Coggrave *et al.* 2006).

No qualitative papers on this topic in this population were identified by the present authors, and it is generally neglected in qualitative papers on MS. Within other neurogenic

populations, such as stroke, there is also a lack of qualitative research relating to bowel dysfunction. However, one paper was identified that investigated the problematic aspects of FI in relation to the experience of adults with spina bifida (Johnsen *et al.* 2009). Eleven participants with spina bifida and FI were interviewed, and they reported 13 specific issues that could tentatively be related to the more general issues of participation, a feeling of helplessness and a sense of shame.

The aim of the present study was to examine the effect of constipation on the QoL of people with MS.

Participants and methods

The present authors conducted a qualitative, interview-based study with 12 people who had MS and constipation. The participants simultaneously took part in a randomized controlled trial that included a treatment group ($n=15$), who received advice on bowel care and were shown how to undertake abdominal massage in an effort to relieve the symptoms of constipation, and a control group ($n=15$), who received advice on bowel care only (McClurg *et al.* 2010). The authors only asked for consent from those in the treatment group because the information sought related to massage as well as constipation. However, only data relating to the effects of bowel dysfunction are included in the present paper since it became apparent that constipation in this population was invariably linked with FI and the interviews were rich in data within this context. Twelve of the 15 participants agreed. Of those who did not take part, one had withdrawn from the study, one had moved house and lived much further away, and one was in relapse. Before beginning the study, ethical approval was obtained from the Office for Research Ethics Committees, Northern Ireland (ORECNI: 08/NIRO2/80).

Participants

Recruitment took place over a 6-month period. Participants self-referred to the study in response to adverts placed in the local MS magazine and website, and as a result of presentations about the proposed study given by the principal investigator (D.M.) at various MS groups and day centres. The participants included individuals who were over 18 years of age, had a confirmed diagnosis of MS, fulfilled the Rome II criteria for constipation, and were able to understand

Table 1. Demographic details of the 12 participants: (SD) standard deviation

| Variable | Results |
|--|------------------|
| Gender (<i>n</i>): | |
| male | 2 |
| female | 10 |
| Age (years): | |
| mean \pm SD | 52.4 \pm 12.32 |
| range | 33–77 |
| Type of multiple sclerosis (<i>n</i>): | |
| secondary progressive | 8 |
| relapsing remitting | 6 |
| primary progressive | 1 |
| benign | 0 |
| Mobility (Expanded Disability Status Scale score): | |
| mean \pm SD | 2 \pm 1 |
| range | 1–5 |
| Treatment for bladder problems* (<i>n</i>): | |
| intermittent self-catheterization | 7 |
| indwelling catheter | 2 |
| Laxative use (<i>n</i>): | |
| no laxatives | 5 |
| Movicol (macrogol) | 4 |
| lactulose | 2 |
| other | 1 |

*N.B. All of the 12 participants had bladder problems.

and agree to the study protocol. Those with a medical history of Crohn's disease, diverticular disease, colon cancer, rectal bleeding or a recent change in bowel function were excluded. Although this was a convenience sample, the participants were a diverse group with ages ranging from 33 to 77 years and disability scores ranging from 1 to 5 on the Expanded Disability Status Scale. Two males and nine females took part in the study (see Table 1 for demographic data).

Methods

Semi-structured face-to-face interviews lasting approximately 60 min were held in the participants' own homes. These sessions were audio-recorded with their consent. Topics were presented neutrally in order not to influence responses and in an open-ended fashion so as to encourage diverse responses. During the exchanges, the interviewer (K.B.) could probe for more information and ask follow-up questions to encourage discussion.

Interviews were used to facilitate each participant's description, without constraint, of his or her unique experience and perspective. All sessions started with a statement that the interviewee was viewed as the expert on their unique condition. This was followed with a review of the purpose of the exercise. The interview opened

with the request, "Tell me in detail about your main experiences of living with MS and the impact it has on your quality of life," and this was followed by asking the participants to further describe the bearing that being constipated had on their QoL. The questions and probes used during the interviews were open and neutral, and were used to elicit in-depth descriptions of the individuals' experiences and to clarify important details. Participants were asked what they meant by being "constipated" (e.g. frequency and difficulty with evacuation) and how they managed their problem (e.g. use of laxatives, diet and digital stimulation). They were asked to give examples of the impact of constipation on their own lives and those of their families; for example, how it affected them both physically and mentally. The participants were also asked how taking laxatives could affect them and their QoL. Difficulties in discussing constipation with their HCPs and family were investigated, as were their thoughts on any sources of information available to them.

Questions were also used to guide the participants back to the focus of the interview when they strayed from the topic. At the end of the session, participants were asked if there were any other important points that they would like to make about their constipation.

Analysis

The interviews were transcribed verbatim and the accuracy was verified by a random sampling of three texts. Each transcript was then read multiple times in order to establish a sense of the whole interview. This initial step was completed separately by two of the authors (K.B. and D.M.). Next, key experiences referred to by the participants were identified. These were labelled as units of meaning. Code words were attached to each meaning unit. The code words used were concrete and descriptive of the ideas expressed in the text. This second level of analysis was completed separately by K.B. and D.M.

The next stage was completed jointly by K.B. and D.M., and involved comparison of and debate about the meaning units. Because these were deliberated and discussed, the meaning units were also clustered into common categories. A summary of each participant's transcript detailing his or her themes/meaning units and associated text was then prepared. All meaning units relating to each thematic heading were colour-coded within the text and then listed for each participant, thus establishing an audit trail.

Further joint discussion then took place regarding the themes. This involved returning to the original transcripts, agreeing themes and debating any potential blind spots that either of the researchers might have had. Themes were then updated to ensure that the essence of the transcripts had been captured. All identifiable data (e.g. participant or place names) have been changed.

Results

The participants framed their observations regarding the impact of constipation with one core theme: spoiled normal identity (i.e. not feeling normal), brought about by the reactions of others, culminating in a sense of social stigma. The main strands were the associated aesthetics (i.e. how much the condition upsets others), decreased self-esteem and loss of control. This was confounded by embarrassment, and the reluctance of patients and clinicians to talk about the problems pertaining to a sense of isolation. Furthermore, inconsistent advice and information often led to self-management by trial and error, which sometimes had disastrous consequences.

Loss of normal identity

The loss of normal identity was the major theme that was present in all the interviews, with participants expressing feelings of social disapproval because they felt different from the norm. They stated that they were embarrassed and fearful, and felt that others often treated them with derision or embarrassment, which stopped them going out socially.

Yvonne, a 60-year-old female, said:

“I would also suffer from constipation with a lot of build up of wind sometimes. I would sort of think a lot of people, they seemed, you know, and look at you funny. . . I think, if I spoke about it, some people would laugh, they wouldn't understand . . . maybe . . . not sort of educated enough in that way.”

Jan, a 35-year-old female, described constipation as a taboo subject:

“It is something people would prefer to ignore . . . it's a huge problem. I had a lady about 4 months ago who rang me – one woman to another – and she could go up to 3 weeks [without a bowel movement]. People are trying to . . . trying to find their own way round it, you know.”

During the interviews, it also became apparent that some participants had difficulties with self-perception and self-esteem. For example, Karen, a 27-year-old female, stated that constipation was a “massive feature” of her life and used emotive language to describe how it made her feel disgusted with herself:

“I can go for maybe 14 days without going to the toilet once, and I mean, it's indescribable how that makes you feel because you feel, you feel completely exhausted all the time and you just feel unconfident. And you don't want to leave the house because you feel disgusted with yourself, because your stomach is, you know, is so full, and you feel so bloated and uncomfortable, and it's just, it's dreadful.”

Yvonne had similar feelings:

“But when you are constipated, you feel bloated and horrible. You know, you put on something like that [leggings] and you look in the mirror and you're just disgusted with yourself. You know, like, ‘Oh, I can't, this is awful.’ I hate myself sometimes. You have no self-esteem anymore.”

Daily impact

Bowel problems had a big impact on the everyday structure of the participants' lives. All of the interviewees reported that they had to plan everyday routine events around their bowel habits. Because of their fear of FI, they reported knowing exactly where the toilets would be (mapping) if they had to go somewhere, or it was the first thing they noted if they were in unfamiliar surroundings. Karen described how constipation affects her whole mood and self-image:

“But if I am feeling terrible, there [have] been times, maybe my fiancé and I have got dressed up to go out, and [I'm] just feeling, look I can't do this. I can't unless I go to the loo. And it takes over your life a bit. Any restaurant or bar or pub, anything like that, always the first thing I do is, ‘Where is the loo?’ and it becomes an obsession with your life.”

Three participants would not go out of the house unless they had been to the toilet to pass a stool. For Louise, a 53-year-old female, this can mean sitting on the toilet for hours, and if she does not go, she stays in the house. For Thomas, a 70-year-old male, it means that he is housebound for 2 days a week (the days after he takes his laxatives), so he has to plan his week around

these 2 days. Kathy, a 35-year-old female, either won't go out or brings a complete change of clothes.

Jan dreaded going away because any change in routine upsets things:

“... I would say, um ... quite ... a fair wee bit in that, I would maybe be going ... this would be my fifth day without having a movement and we are going to X [approximately an 80-km drive], and I would know ... maybe ... sometimes, if you get something into your mind, it will happen. And I would just ... I would put in my morning trying to get to the bathroom and trying to get something done, and nothing would happen, and in my head, I would think, ‘Do you know, we will not be in X [about half way]. ... I will have to get to a toilet pronto, really, really quickly,’ and I would be panicking, my husband saying, ‘Get a grip, there are public toilets.’ I know where all the public toilets are, you know, and the ones that are good and the ones that aren't, and that's because of constipation. And because ... you know, I will have ... maybe taken something yesterday, but I am not going to take anything tomorrow because we are going to be going to X tomorrow, say, or somewhere else tomorrow. And ... and then that sort of upsets the applecart and puts you back a bit so ... yeah ... constipation, um ... it has had a big impact, a big bearing on my life.”

Faecal incontinence was inextricably linked with constipation for some participants and was invariably associated with laxative use within this group. One episode of FI was a life-changing experience and the fear of a recurrence was enormous. It was emphasized that it was much more antisocial than urinary incontinence (UI) because of the associated smell, and problems with getting changed and washed. Louise talked about being mentally scarred after having an “accident” in a restaurant, and Yvonne no longer enjoys going out because of her dread of it happening again. Faecal incontinence was not something that some of the participants easily admitted to, even within these interviews, and it was often only during the second half of the session that it would become apparent that they had had one or more episodes. One respondent, Ian, a 25-year-old male, was even unable to talk about the possibility of FI and would turn the conversation around by talking about UI. He could not bring himself to say the words: “Um,

just sort of leaks and stuff. But not the other side.”

Physical symptoms such as pain, discomfort and excess wind are associated with constipation as well, and it also exacerbates other clinical signs of MS such as bladder problems and fatigue. Karen said constipation “slows you down, you feel all the time you need to go to the toilet and you think you have gone, half an hour later you think, ‘Oh, I still need the toilet,’ and you have to go back a second time”.

Overall, it made the participants very anxious and uncomfortable, and could cause pain on defecation if the stool was very hard. Louise described it as “like sitting on a brick all day”. She also mentioned the effect that constipation had on her bladder: “I was like constipated all the time, it was like I felt there was just a constant pressure that I had to pee-pee.”

Reluctance of patients and healthcare professionals to discuss bowel problems

Because of the stigma attached to the condition, the participants were reluctant to talk about their bowel problems, and they felt that many clinicians/HCPs were also embarrassed to bring these up, much more so than any other symptom of MS. Karen said that she would have found it easier if someone else raised the subject with her rather than her having to initiate it:

“Well, you don't really want to talk about going to the loo to somebody. But when you talk about something that is intimate like that, it is difficult, very difficult. Especially if the doctor is a man.”

It was also something that was difficult to discuss with the family. For example, Karen continued:

“You're not allowed to say anything. People don't want to. And then, um, my brothers and sisters, where there's a problem with incontinence, it's like the *elephant's in the room*.”

As Jan said:

“You just get on ... hang your head. It's not something you want to broadcast.”

Participants also stated that they did not feel comfortable discussing bowel problems because they did not know the language to use. They often perceived common terminology as being either crude (e.g. “shit”) or childish (e.g. “poo”).

Lack of consistent advice

Many of those interviewed felt that treatment of bowel dysfunction was mainly a trial-and-error

process, there was little guidance and that conflicting advice was often given. It was also felt that there was a general lack of information. Some participants tried to control their bowel function with diet, especially by eating fruit and taking natural remedies. The use of laxatives was common; however, a repeated observation was that regulation of this medication was by trial and error, which sometimes had catastrophic effects that meant some participants stopped using these. As Louise stated:

“It’s always been . . . sometimes with disastrous results, learning which bowel . . . which stimulant you can use and can control. Some of them are quite . . . like rocket fuel.”

Lorna, a 50-year-old female, blamed taking laxatives for causing one episode of FI:

“Not so much now [i.e. being worried about having another accident] because I don’t take the laxative. And I think it was with the laxative that this happened. And I didn’t have the sensation of needing to go, it was just warm. It has not happened for ages and I’ve stopped the laxative.”

Digital stimulation was used by one of the male participants, but again, this was not something the participants found easy to discuss:

“It sounds a bit rough, but it’s the truth. To try and get yourself to move. So . . . when you have put your fingers inside you and you go right now. . . I would love to be able to take all this away. . .”

It was also evident that FI was difficult to manage and pads were often inadequate, so a complete change of clothes was nearly always packed. It is much more difficult to disguise, as Anne said, “because there is a smell associated with it as well, which is a big problem”.

Loss of control

Participants also described a feeling of losing control of their body, which was worse than any of the other symptoms. Yvonne said:

“Bloating is terrible! Now I bought a pair of trousers in May, and last week, I was really bloated and eventually got one button up here and the zip wouldn’t really go up. I usually have a flat tummy, I can’t do anything to stop it.”

Sheila, a 37-year-old female, agreed:

“The bloating is worse than not going to the toilet because it is always on my mind. I am very, very weight conscious, eat fruit and vegetables, but to no avail because your body is letting you down.”

Karen stated that, “Like with my eyesight, I’ve learned to live with partial sight, but with the bowels, it’s like you’ve no control over it.”

Discussion

Constipation has a significant impact on the QoL of people with MS. As Goffman (1971, p. 353) put it, “an organic defect with visible symptoms may be a minor thing according to a medical or biological frame of reference, but is likely to be of tremendous significance socially”. The impact of chronic constipation on those who also have another long-term condition such as MS has not been evaluated before.

The overriding theme that emerged from the interviews was the loss of normal identity arising from the social stigma associated with bowel dysfunction. This feeling was confounded by not being in control of one’s bodily functions. Goffman (1963) described social stigma as an “undesired differentness”, an attribute that is deeply discrediting. The associated loss of normal identity involves a labelling process in which individuals, by categorizing stereotypes, recognize the deviant as being undesired. Public stigma, or a negative attitude held by a community member, has consequences for people with stigmatizing conditions. These consequences can be exacerbated by six factors: concealability, course, disruptiveness, aesthetic qualities, origin and peril (Goffman 1971). All of these factors can be related to people with MS and constipation.

For example, concealability refers to whether the condition is obvious or can be hidden. The participants often felt that their constipation was obvious to others because it made them feel bloated and uncomfortable. If it was accompanied by FI, then this was much harder to conceal, and it was stated that this was significantly worse than urinary incontinence because it was much more difficult to contain/change or hide because of the smell. The participants also stated that FI had a large impact on their lives since their whole routine could be centred around going to the toilet, and if anything interrupted this (e.g. going on a holiday), then they worried. They also felt that there was a lack of empathy: families and/or HCPs did not

really want to know about the problem, and because it was not often discussed, the participants thought that it should be something they could treat themselves. The aesthetics of bowel dysfunction were an important factor, i.e. how much the condition upsets others by way of the five senses. Participants reported how difficult they found it to control the passing of wind or sometimes faeces. Indeed, going to the toilet to pass a stool or the breaking of wind are taboo subjects that are often associated with feelings of disgust, especially because of the associated smell and management of soiling. The related bloating makes the participants feel unattractive. Finally, peril refers to the amount of fear and danger associated with an individual's illness. Patients fear the unknown of disease progression and the loss of control of their body functions. Corrigan *et al.* (2006) stated that this "public stigma" can lead to personal responses, internalization and ultimately "self-stigmatization", which is associated with lowered self-esteem, depression, anxiety and decreased service utilization. It was evident from the interviews that many of the participants had very low levels of self-esteem.

Service utilization in terms of seeking help was low. Although bowel control is not a purely reflexive process, it is among many bodily functions that individuals find difficult to describe. This makes communication difficult both for the individual attempting to describe his or her problem, and for the health professional trying to help the patient by teaching him or her techniques for improved control. A person who has never discussed these bodily functions before may lack the internal constructs needed to describe what is happening verbally, or may genuinely not understand how to express a change from a former state that was never consciously articulated or even thought about before (Norton 2004). The participants reported that they found it difficult to talk to clinicians about anything to do with their bowels. They also stated that they believed that it was not something worth bothering a HCP with because it was not life-threatening, and some thought that it had nothing to do with their MS. Healthcare professionals need to be educated about how to approach such sensitive subjects since their attitudes can encourage people to access legitimate healthcare or deter them. All HCPs have both conscious and unconscious attitudes, and likewise, are members of a society as well as of a professional discipline (Norton 2004).

Bristol Stool Chart

| | | |
|--------|--|--|
| Type 1 |  | Separate hard lumps, like nuts (hard to pass) |
| Type 2 |  | Sausage-shaped but lumpy |
| Type 3 |  | Like a sausage but with cracks on its surface |
| Type 4 |  | Like a sausage or snake, smooth and soft |
| Type 5 |  | Soft blobs with clear-cut edges (passed easily) |
| Type 6 |  | Fluffy pieces with ragged edges, a mushy stool |
| Type 7 |  | Watery, no solid pieces. Entirely Liquid |

Figure 1. The Bristol Stool Chart (Lewis & Heaton 1997).

Language is all-important: it was interesting that some of the participants in the massage study greatly appreciated the opportunity to learn not only more about the possible causes of their constipation, but also the acceptable words to describe their symptoms (e.g. "poo" and "faeces"). Furthermore, the Bristol Stool Chart (Fig. 1) gave them a means of describing their symptoms. Healthcare professionals often use terminology that either intentionally or unwittingly takes control away from people because they do not understand words such as micturition, defecation, urethra and detrusor. Common public vocabulary for excreta or elimination behaviour often includes "baby" words, euphemisms, slang or swear words, which many people are reluctant to use in a "professional" setting. This sets the stage for potential misunderstandings and poor communication.

Potential criticisms of the present study are that only a small number of interviews were conducted, and that this self-selected sample was possibly made up of those who were seeking additional help (i.e. who were unhappy with their current treatment) and were affected more severely by their constipation. However, the themes were saturated even with this sample size, and it is the present authors' experience that treating patients with MS for bladder problems

invariably opens up discussions relating to bowel issues.

Any healthcare interaction must be a two-way process, but the patient's perspective has been relatively underexplored (Norton 2004). Furthermore, a quick and easy remedy is seldom found in chronic conditions. As professionals, we need to be much more aware of the impact that constipation has on people with MS and be proactive in asking the right questions.

Individuals with MS exhibit multiple physiological symptoms related to the musculoskeletal system (e.g. spasticity and muscle weakness), the autonomic nervous system (e.g. bladder, bowel and sexual dysfunction) and the central nervous system (e.g. cognition, affect, pain and fatigue). The occurrence of these symptoms varies within and between patients with MS based on the extent and location of the lesions, and on the exacerbation and progression the disease. Common symptoms in MS are interrelated: one can exacerbate another or can be caused by the treatment of yet another. Salter (1997) suggested that patients need three types of support from HCPs: emotional, informational and instrumental (practical aid). There seems to be a deficit of support, information and treatment for those with MS and bowel dysfunction.

Goffman (1971) proposed the concept of "the wise": knowledgeable people who know about a stigmatizing condition and the secret life of the stigmatized individual. Wise people can offer patients practical help and sympathy without the pretences and face-saving performances that are usually needed (Norton 2004), and those HCPs who see people with MS need to be such wise practitioners.

Conclusion

To the best of the present authors' knowledge, this is the first study describing the impact of constipation on someone with MS, as reported by the person themselves. It gives an account of the insider's experiences, contributes to our understanding of the impact of MS, and enables the evaluation of treatment and information-giving options. The results of such qualitative studies have implications for interpreting and understanding the experiences of people with the condition and have the potential to influence the clinical management of symptoms. The expert, i.e. the person with MS, has a role to play in the education of clinicians and researchers. Such individuals can provide us with valid and valu-

able insights into the lived experience of constipation, and indeed, other symptoms associated with the condition that have the potential to direct clinical assessment, intervention and further research.

Healthcare providers need to take up this challenge so that their patients can be offered information and treatment that is caring and sensitive to their needs, and can feel cared for as a person and not as an illness. The optimal management of the symptoms of MS is clinically challenging, and requires a comprehensive multimodal and individualized approach. In relation to constipation, both pharmacological and non-pharmacological modalities need to be explored with the goals of improving or maintaining function, and preserving QoL.

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