CRITICAL REVIEWS IN ORAL BIOLOGY & MEDICINE

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ABSTRACT

Despite its relatively recent emergence over the past few decades, oral health-related quality of life (OHRQoL) has important implications for the clinical practice of dentistry and dental research. OHRQoL is a multidimensional construct that includes a subjective evaluation of the individual's oral health, functional well-being, emotional wellbeing, expectations and satisfaction with care, and sense of self. It has wide-reaching applications in survey and clinical research. OHRQoL is an integral part of general health and well-being. In fact, it is recognized by the World Health Organization (WHO) as an important segment of the Global Oral Health Program (2003). This paper identifies the what, why, and how of OHRQoL and presents an oral health theoretical model. The relevance of OHRQoL for dental practitioners and patients in community-based dental practices is presented. Implications for health policy and related oral health disparities are also discussed. A supplemental Appendix contains a Medline and ProQuest literature search regarding OHRQoL research from 1990-2010 by discipline and research design (e.g., descriptive, longitudinal, clinical trial, etc.). The search identified 300 articles with a notable surge in OHRQoL research in pediatrics and orthodontics in recent years.

KEY WORDS: quality of life, health services research, patient outcomes, evidence-based dentistry/health care, community dentistry, psychosocial factors.

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Oral Health-related Quality of Life: What, Why, How, and Future Implications

INTRODUCTION

Despite its relatively recent emergence over the past few decades, oral health-related quality of life (OHRQoL) has important implications for the clinical practice of dentistry and dental research. OHRQoL is an integral part of general health and well-being and is recognized by the WHO as an important segment of the Global Oral Health Program (WHO, 2003). International health campaigns utilize advertising and marketing strategies to enhance well-being by portraying positive oral health images that represent global health values. Efforts range from the elimination of dental pain to illuminations of aesthetic images using 'attractive' smiles with 'white' teeth. Such efforts are integrated into what is now referred to as OHRQoL. The specific aims of this paper include: (1) defining OHRQoL (the What); (2) explaining the importance of OHRQoL for dental practice and research (the Why); (3) describing how OHRQoL is used in research and examining research trends over time (the How); and (4) identifying implications of OHRQoL research for health policy.

WHAT IS OHRQoL?

In response to the WHO's definition of health as "a complete state of physical, mental, and social well-being and not just the absence of disease" (WHO, 1948), health service researchers have focused on health as a multidimensional construct. This concept of health status embraces the biopsychosocial model of health into which symptoms, physical functioning, and emotional and social well-being are incorporated (Kleinman, 1988). Quality of life (QoL), or individuals' "perceptions of their position in life in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns" (WHOOOL, 1995, 1405), is now recognized as a valid parameter in patient assessment in nearly every area of physical and mental healthcare, including oral health. Since Cohen and Jago (1976) first advocated the development of sociodental indicators, efforts have been invested in developing instruments to measure OHRQoL (Slade and Spencer, 1994; Broder et al., 2000; McGrath and Bedi, 2003). Further, the opportunity arose to consider how oral health affects aspects of social life, including self-esteem, social interaction, school and job performance, etc. Researchers began to postulate how oral health is related to health-related quality of life (HRQoL) (Gift and Atchison, 1995) and to understand the interrelationships between and among traditional clinical variables (like diagnosis), data from clinical examinations, and person-centered, self-reported health experience. The subjective evaluation of OHRQoL "reflects people's comfort when eating, sleeping and engaging in social interaction; their selfesteem; and their satisfaction with respect to their oral health" (DHHS, 2000, 7). It is the result of an interaction between and among oral health conditions, social and contextual factors (Locker et al., 2005), and the rest of the body (Atchison et al., 2006).

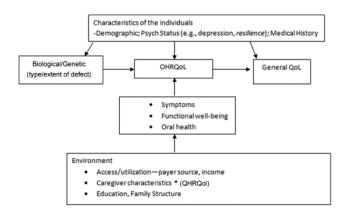


Figure 1. Theoretical model for OHRQoL. *Applicable for children only.

Our theoretical model for OHRQoL, which incorporates biological, social, psychological, and cultural factors, is depicted in Fig. 1. This model, adapted from Wilson and Cleary (1995), is built on psychological and social science theory and epidemiological findings (Patrick and Erikson, 1993; Barbosa and Gavião, 2008). This framework links health status or clinical variables (e.g., type/extent of defect), functional status (e.g., speech), oral-facial appearance, psychological status, OHRQoL, and overall QoL. The model recognizes the effects of environmental or contextual factors (e.g., sociocultural factors, education, family structure) and access to care on oral health perceptions and related QoL. Theoretically, OHRQoL is a function of various symptoms and experiences and represents the person's subjective perspective.

With increasing focus of health policy to address health promotion and disease prevention, HRQoL and OHRQoL have come to incorporate both positive and negative perceptions of oral health and health outcomes (Broder and Wilson-Genderson, 2007). Thus, assessments of oral health can reflect both negative impact and enhancement of self and well-being. For example, people may seek oral healthcare for preventive (e.g., cleanings) or elective (e.g., orthodontics) treatment. Health psychologists have recognized that psychological assets such as optimism and resilience correlate with an individual's QoL, particularly how well she or he is able to cope with disease and poor health (Broder, 2001; Strauss, 2001; Lopez et al., 2003). This model incorporates positive psychology which has far-reaching implications in health delivery, since human strengths such as coping and social connectedness have been linked to better immunosuppressance, health outcomes, and mortality (Lopez et al., 2003). Common dimensions in OHRQoL instruments are given in Fig. 2, along with specific examples of items associated with each dimension. While traditional factors like oral health symptoms are illustrated in this figure, factors such as social and emotional well-being incorporate positive health states such as happiness and confidence. Recent OHRQoL instruments, like the Child Oral Health Impact Profile (COHIP), attempt to identify the impact of treatment (e.g., satisfaction) along with the "positive



Figure 2. Dimensions comprising oral health-related quality of life (OHRQoL).

*Excludes non-patient groups.

influence of oral health and the appearance of the face and teeth on overall health and well-being among patients and the non-treatment-seeking individuals" (Broder and Wilson-Genderson, 2007, 21). Positive health attributes have also been incorporated into measures with youth (Patrick *et al.*, 2002), adults (McGrath and Bedi, 2003), and older persons (Atchison and Dolan, 1990). In short, OHRQoL assesses positive and negative dimensions across the life course.

WHY IS OHRQOL IMPORTANT?

OHRQoL is important for both theoretical and practical reasons. The Surgeon General has identified OHRQoL as a health priority (DHHS, 2000), and "QoL issues are now at the forefront of public health policy" (Slade, 2002, 29). The Surgeon General's report and conference, *The Face of the Child*, highlighted the importance of children's oral health to their overall health and well-being and the profound impact that oral health can have on children's QoL (Mouradian, 2001; Wilson-Genderson *et al.*, 2007). Oral health can affect anyone's life; OHRQoL research has shown its utility in the study of diverse populations including patients with oral cancer (Ship, 2002), toddlers with early childhood caries (ECC) (Filstrup *et al.*, 2003), or children with craniofacial anomalies (Broder, 2007). Our literature review (see Appendix) provides an overview of the range of OHRQoL research and methodological designs.

Assessment of OHRQoL allows for a shift from traditional medical/dental criteria to assessment and care that focus on a person's social and emotional experience and physical functioning in defining appropriate treatment goals and outcomes (Christie *et al.*, 1993). Patients' subjective evaluation of the

healthcare decision-making process is changing the dynamics of clinical practice and health outcomes monitoring and research (Inglehart and Bagramian, 2002). Medical and dental research on HRQoL has flourished because of: (1) the patient's more active role as a member of the treatment team; (2) the need for evidence-based approaches in health practices; and (3) the fact that many treatments for chronic diseases fail to 'cure' the health condition, thereby elevating the importance of HRQoL as a valuable health outcome variable (Najman and Levine, 1981).

Finally, OHRQoL is important because of its implications for oral health disparities and access to care. Unfortunately, socioeconomic and racial/ethnic oral health disparities constitute a major social problem (Petersen *et al.*, 2005). Health disparities can be explained, in part, by limited access to care. Locations within developing countries may have minimal dental health professionals, and rural areas often lack facilities offering dental services. In developed countries, treatment access is limited by high costs and sometimes by transportation difficulties (Sisson, 2007). OHRQoL can be useful in measuring the impact of oral health disparities on overall health and QoL. Policy implications are discussed in the "Implications" section.

HOW IS OHRQOL USED IN RESEARCH?

Based on the paradigmatic shift toward a patient-centered, biopsychosocial approach to oral healthcare, OHRQoL has become central to dental research. In this section, we identify: (1) considerations for assessing OHRQoL; (2) the use of OHRQoL in survey research; and (3) utilization of OHRQoL as an outcome measure.

Considerations for Assessing OHRQoL

There are multiple considerations when OHRQoL is used in research. First, it is important to determine the specific purpose of the OHRQoL assessment, since research applications can vary [e.g., assessing oral health impact by comparing treatment utilization of a community, comparing impact within/across age group(s)]. The OHRQoL assessment tool should discriminate between and among those applications by extent of the condition (e.g., disease status) and potentially across diagnostic or treatment-seeking groups (e.g., orthodontic vs. pediatric dental).

Another consideration is the use of generic vs. disease condition-specific instruments. Disease-specific measures may be advantageous over generic measures. First, they were developed for specific conditions (e.g., cancer) to tap symptoms and impacts associated with that condition, which may increase their sensitivity compared with that of generic instruments. For example, the disease-specific Oral Health Impact Profile (OHIP) is more highly correlated to oral health conditions than is the generic QoL measure, the Short Form Health Survey (SF-36) (Lee et al., 2007). While a generic scale might query about fatigue or bodily discomfort, an OHRQoL measure would query about oral pain. A second advantage of disease-specific over generic measures is that generic tools generally have higher 'floor effects' (i.e., no impact), since many of the symptoms tapped may not be prevalent or relevant among samples of individuals seeking dental care. OHRQoL measures are specific to oral health (e.g., teeth, mouth, face) but are general in that a range of oral symptoms and impacts is included (*e.g.*, bleeding gums, appearance concerns). Thus, OHRQoL measures are appropriate across multiple oral health conditions but may not be sensitive to people seeking care for a health condition that does not have oral health manifestations, like Sickle Cell (Ralstrom, 2010).

One must keep in mind, however, that if a condition-specific OHRQoL measure is being developed, the condition and/or its symptoms must also be responsive to treatment. In short, the measure must have effective evaluative properties. If the OHRQoL assessment is meant to be used for population-based epidemiological sampling (e.g., to assess deficits, negative impact), it should include a wide range of oral symptoms to properly tap a multitude of oral impacts. Thus, a generic measure is likely less responsive to change than an OHRQoL assessment used in a study focused on a single disease/condition.

OHRQoL instruments can also address issues related to agespecificity and oral health. Since oral health is "strongly agedependent" (John et al., 2004), differences in OHRQoL have been found between children and adults (Tapsoba et al., 2000). While many instruments exist to measure adult OHRQoL (Slade, 2002; Al Shamrany, 2006), recent efforts have focused on measuring children's OHRQoL (COHRQoL). COHRQoL presents unique challenges, because children's dental, facial, and cognitive development changes drastically throughout childhood and adolescence. These challenges make proxy ratings a valuable resource for verifying (or contradicting) children's self-reported OHRQoL (Eiser and Morse, 2001; McGrath et al., 2004) and important for providers and researchers to utilize. It has been demonstrated that, compared with those of orthodontic and pediatric dental patients, children and caregiver ratings on OHROoL were most discordant in the craniofacial population, with caregivers rating their children's QoL lower than the children rated themselves (Eiser and Morse, 2001; Wilson-Genderson et al., 2007). Therefore, obtaining both child and caregiver reports with OHRQoL instruments, like the COHIP, provides a more accurate depiction of COHRQoL than does either the child or caregiver report alone (Wilson-Genderson et al., 2007). Further, access to care and utilization can be dependent on caregivers' perceptions. Other proxy measurements include teacher ratings (e.g., bullying about teeth, face, or mouth; social acceptance) given the amount of time children spend in school with their peers. For preschool children, caregiver assessments have been developed to measure oral health impact (Filstrup et al., 2003; Pahel et al., 2007).

OHRQoL in Survey Research

OHRQoL is utilized in health services research to examine trends in oral health and population-based needs assessment. Epidemiological survey research has examined trends in OHRQoL (e.g., decayed surfaces), identified individual and environmental characteristics that affect OHRQoL (e.g., income, education, etc.), and aided in needs assessment and health planning for population-based policy initiatives. Research has found that certain groups are at greater risk for low OHRQoL. For example, in Canada, children from low-income families have poorer OHRQoL than children from high-income families,

indicating a socio-economic disparity (Locker, 2007). While the individual characteristics and environment portions of our health model can theoretically predict outcomes, research has also found that sociodemographic factors (e.g., race, education, and transportation difficulties) are strongly associated with low OHRQoL for elderly dentate patients in Alabama. Yet, such associations were not significant for the edentulous study participants (Makhija et al., 2006). Thus, the relationship between sociodemographic characteristics and OHRQoL is not clear-cut. For example, Latino immigrants report higher OHRQoL than non-Latino whites, although this difference is limited to firstgeneration Latinos (Sanders, 2010). Nevertheless, using data from the NHANES and National Health Survey for Children, the Surgeon General's Report purports that oral health disparities and reduced OHROoL in the US are most prevalent among racial and ethnic minorities and those with socio-economic disadvantages (DHHS, 2000).

Research has revealed that certain medical, dental, and emotional conditions are also associated with low OHRQoL. For example, women with HIV (Mulligan et al., 2008), individuals with dental anxiety/fear (Mehrstedt et al., 2007), and individuals with periodontal disease (Ng and Leung, 2006) have lower OHRQoL compared with the general population. There appears to be a consistent association between clinical variables (like DMFS) and OHROoL across age groups (Mason et al., 2006; Jensen et al., 2008; Lawrence et al., 2008; Kim et al., 2009). In a recent study that compared children seeking pediatric dental, orthodontic, or craniofacial care, OHRQoL varied not only across clinical groups but also by extent of defect (Broder and Wilson-Genderson, 2007). Thus, the greater the untreated dental decay, the lower the QoL, and the greater the malocclusion (overiet), the lower the OoL. Further, those with craniofacial conditions had lower QoL than the other treatment groups. Such baseline assessments may inform health practitioners of specific areas of focus from the patients' perspectives. Thus, extent/type of medical condition is included in our theoretical model.

Various factors associated with the *symptoms/functional* well-being/oral health sector of the theoretical model have been found to affect OHRQoL. For example, chewing ability has been found to affect the OHRQoL of the elderly (Kim et al., 2009). OHRQoL is also associated with perceived need for dental treatment, poor self-rated health, reduced mental health, fewer teeth, and relatively poor cognitive status for elderly persons with disabilities (Jensen et al., 2008). Dental aesthetics and facial appearance are also associated with OHRQoL (Klages et al., 2004; Broder and Wilson-Genderson, 2007).

Other researchers have considered mediating factors that can affect oral healthcare and health status. According to our theoretical model, it is important to understand how *characteristics* of the individual (e.g., self-concept, psychological well-being) may interact with health perceptions. While past research has focused on negative effects, like depression and anxiety, currently, investigators are examining positive attributes like resilience and its impact on healthcare access and utilization and health perceptions. Barbosa and Gavião (2008) found that the relationship between clinical variables and HRQoL outcomes is mediated by various personal, social, and environmental factors. Across a variety of conditions, like temporomandibular

disorders (TMD), anxiety and depression may be mediating or moderating variables in etiology, health utilization, and responsiveness to care (Gale and Dixon, 1987; Litt *et al.*, 2009). Such findings have been supported by Patrick and colleagues (Patrick *et al.*, 2002, 2007) in assessing QoL factors in adolescents across clinical groups. These findings may have implications in the evaluation of treatment needs and outcomes.

Including OHRQoL in survey research adds a powerful dimension in the planning and development of health promotion programs. By identifying groups who are vulnerable for low OHRQoL (e.g., pregnant women, older persons), investigators can use data from survey research to create programs aimed at improving oral health and elevating OHRQoL. Thus, integrating oral healthcare into routine nursing programs is suggested (Jung and Shin, 2008). Other programs range from Head Start for preschool children to federally funded health centers for indigent or homeless adults.

OHRQoL as an Outcome Measure

More recently, OHRQoL assessments are being incorporated into observational clinical studies and trials to measure efficaciousness of treatment with the goal of improving care (see Appendix Table 1). Longitudinal studies involving OHRQoL seek to measure changes in scores from baseline to post-treatment. Currently, the second author is the PI on a six-center NIDCR-supported project, "Quality of Life in Children with Cleft" (DE018729). This prospective investigation is examining changes in OHRQoL and HRQoL following surgical interventions among school-aged children with cleft conditions. Collecting longitudinal data will allow us to use individual growth models to estimate change trajectories over time (McArdle and Bell, 2000; Moskowitz and Hershberger, 2002). The rationale behind elective interventions is that they improve QoL. However, subjective evaluations (like OHRQoL) are critical for determining if the interventions have the intended effect, and if that effect changes over time. In line with evidence-based care, it is crucial to understand treatment effectiveness from the patients' perspectives and the interrelationships between specific oral/facial issues and general QoL, psychological factors like depression or resilience, and family variables like cohesiveness.

Researchers studying oral health problems have used OHRQoL as an outcome measure to determine the effect of treatment on QoL. Awad *et al.* (2000) found that, compared with the use of conventional dentures, mandibular implant overdentures significantly improved OHRQoL for patients with edentulism in the short term. Likewise, Brazilian adolescents who had orthodontic treatment had better OHRQoL than their non-treatment counterparts (de Oliveira and Sheiham, 2004). Finally, a study in San Francisco found that rehabilitative dental treatment improved welfare recipients' OHRQoL and employment outcomes (Hyde *et al.*, 2006).

The use of OHRQoL as an evaluative outcome measure is congruent with patient-centered care. Along with other clinical assessments, it allows oral healthcare professionals to evaluate the efficacy of treatment protocols from patients' perspectives (Wright *et al.*, 2009). With multiple evaluative tools, professionals are better equipped to accurately weigh the risks and benefits

associated with treatment. In addition, it provides evidence that costs associated with treatment protocols are worth the expense if they generally improve patients' OHRQoL (Slade, 2002). Analysis of data from research using OHRQoL as an outcome measure will also assist patients and their families in treatment decision-making.

Based on our model, OHRQoL assessments can also identify individuals' strengths and weaknesses regarding their QoL. This could be useful in the development of adjunct multidisciplinary service programs, as well as the use of OHRQoL tools to measure outcomes of such interventions. For example, if psychological well-being is found as a deficit area for the elderly, psychological adjunct services may be incorporated into community-based projects. Physical therapy and/or cognitive behavioral therapy have also been utilized in clinical care for individuals with conditions ranging from chronic pain to cleft lip and palate (Kapp-Simon, 1995; Furto *et al.*, 2006; Turner *et al.*, 2006). In short, the multidimensional nature of OHRQoL can be useful for identifying at-risk populations and developing interventions that care for the 'whole' person.

A final consideration in the use of OHRQoL as an outcome measure is addressing and measuring clinically meaningful change. Since the 1980s, HRQoL researchers have known that statistically significant changes over time may not be meaningful to patients (Jaeschke et al., 1989). Researchers typically report statistical significance to demonstrate the importance of their outcome studies. Nonetheless, sample and size variation within these studies has played a very important role in determining statistical significance. While significant results showing pre-/ post-group change may be appropriate for use in populationbased health policy, it may not be appropriate for clinical care outcomes or clinical trials measuring within-group effects (Osoba et al., 1998; Turk, 2000; Koretz, 2005). According to Cella and co-workers (2002), determining the clinical significance of HRQoL data requires that attention be given to overall group differences and individual assessments. For this to be achieved, two issues need to be resolved: (1) whether a "statistically significant difference" between experimental and comparison groups has "clinical meaningfulness"; and (2) whether a "statistically significant difference" at the group level has relevance for "clinically meaningful change" at the individual level. HRQoL research has emphasized that this aspect of change can have patient-oriented applications. Despite the rise of clinically meaningful outcome reports across medical conditions (Sloan et al., 2002; Wyrwich et al., 2005), there is a dearth of published studies assessing clinically meaningful change in the oral health arena.

IMPLICATIONS OF OHRQoL RESEARCH AND HEALTH POLICY

The pervasive problem of low oral healthcare utilization and poor oral health (Sisson, 2007) is often the result of unequal access to care (Petersen *et al.*, 2005; Edelstein, 2006). Given our current economic and healthcare challenges and the resulting political debate around curtailing healthcare costs, access to care is a major policy issue. Using the association between oral health conditions and QoL can be an effective mechanism to

communicate with policymakers to reveal the importance of oral health and equal access to care (Al Shamrany, 2006). With increasing treatment options and the diversity of patient samples, we should consider sociocultural and psychological factors when assessing needs, outcomes, and clinical practice. Given the disparities in access to care and treatment rationing due to costs, comparing QoL across treatment groups may facilitate decision-making for patients, healthcare providers, and policymakers.

Recent legislation aims to improve oral health by increasing access to care and focusing research attention on subjective patient evaluations related to OHRQoL. For example, the Patient Protection and Affordable Care Act, Public Law 111-148, presents a wide range of tools, resources, and requirements to ensure that Americans have high-quality, patient-centered healthcare coverage. Currently, community health centers have been identified and grant-supported by the US Department of Health and Human Services' Health Resources and Service Administration (HRSA) as a mechanism to improve access such centers may also include dental treatment. In 2009, almost 3.4 million individuals received dental services through these centers (HRSA, 2010). Given the prevalence and preventable nature of dental caries, measuring the impact of these services before and after treatment may improve evidence-based decision-making related to treatment needs, effectiveness, and policy perspectives.

Given the importance of health disparities to public policy, it is not surprising that NIH and NIDCR are committed to supporting oral health disparities research. NIDCR has supported Centers for Research to Reduce Oral Health Disparities since 2001. To date, both the Center at Boston University and CAN-DO at the University of California are studying the effect of early childhood caries (ECC) on young children's OHRQoL (Cunnion *et al.*, 2010).

Presently, the Agency for Healthcare Research and Quality (AHRQ), NIDCR, and other NIH institutes are seeking to sponsor research in comparative effectiveness of care. The Patient-Centered Outcomes Research Institute has also been created to evaluate treatment efficacy and provide better information for patients and their doctors. Such efforts emphasize and support the application and relevance of HRQoL assessments.

The NIH has incorporated HRQoL research into its roadmap, emphasizing patient-oriented outcomes. Currently, there are at least three NIDCR-funded projects examining OHRQoL across the lifespan from childhood to old age, across geographic regions (e.g., urban, rural, and international), and for chronic conditions such as cleft lip and palate. NIDCR also supports research that examines correlates of OHRQoL (e.g., body image, health beliefs) and research that seeks to uncover social determinants of oral health.

Congruent with the NIH roadmap, dental-practice-based research networks (DPBRNs) have been created to enhance care and improve community health. These networks are grounded in evidence-based dentistry, which integrates scientific evidence, dentists' clinical expertise, and patients' needs and preferences (ADA and Center for Evidence-Based Dentistry, 2010). An integral part of DPBRNs includes subjective patient evaluations

about their oral health and treatment experiences. According to the Practitioners Engaged in Applied Research and Learning (PEARL) Network, by measuring OHRQoL in their patients, oral health professionals can enhance evidence-based care (Botello-Harbaum *et al.*, 2010). Currently, the PEARL Network is completing longitudinal protocols to compare objective (clinician ratings) and subjective assessments (patient OHRQoL ratings) to measure treatment outcomes. Study findings will elucidate the interrelationships among oral healthcare and QoL factors. The PEARL projects exemplify how patients are an invaluable source of information regarding treatment protocols, outcomes, and how oral health is related to QoL.

In short, applied science is translational, and QoL assessments may be at the hub of evidence-based clinical care. Assessments of health perceptions from patients and community-dwellers can increase our understanding of healthcare access, expectations, and treatment effectiveness.

CONCLUSION

OHRQoL has a multitude of substantive applications for the field of dentistry, healthcare, and dental research as we move from bench to applied science and person-centered approaches to measure treatment needs and efficacy of care. Patient-oriented outcomes like OHRQoL will enhance our understanding of the relationship between oral health and general health and demonstrate to clinical researchers and practitioners that improving the quality of a patient's well-being goes beyond simply treating dental maladies. OHRQoL research can be used to inform public policy and help eradicate oral health disparities. Researchers are beginning to uncover what OHRQoL has to offer, and if recent studies are any indication, the future looks bright indeed.

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