

The Challenges of Providing Culturally Competent Care Within a Disability Focused Team: A Phenomenological Exploration of Staff Experiences

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Abstract

Purpose: The study explored how service providers address the challenges of providing culturally competent care within disability services in the United Kingdom. **Design/Method:** Focus groups and interpretative phenomenological analysis were used to explore the experiences of 20 service providers from a range of professions, working with South Asian families. **Results/Findings:** Two superordinate themes emerged. The first concentrated on difficulties with language and communication and the challenges posed by the use of interpreters. The second included five subthemes that broadly described a five-stage process of dealing with barriers and engagement to service delivery, followed by reflections on the effort made to provide culturally competent care in the face of limited resources and training. **Discussion/Conclusion:** The study makes recommendations for cultural competency within health and social care services.

Keywords

cultural competence, focus group analysis, phenomenology, cross-cultural, South Asian, Indian, Pakistani, Bangladeshi, intellectual disability, learning disability

Review of the Literature

Ethnic minority groups make up 8% of the United Kingdom's population, with South Asians, primarily Indians and Pakistanis, making up the largest ethnic groups (Office of National Statistics, 2001). In the United Kingdom, the term *South Asian* usually refers to people who originate from India, Pakistan, Bangladesh, and Kashmir (British Sociological Association, 2005) and reflects the migratory patterns of South Asians to the United Kingdom. Research has demonstrated that the prevalence of intellectual disabilities among South Asian groups is thought to be almost three times higher than any other communities in the United Kingdom (Emerson et al., 1997). A number of reasons have been postulated for this, including social and material disadvantage, as well as a possible genetic risk factor (Bittles, 2001; Fazil, Bywaters, Ali, Wallace, & Singh, 2002). Despite this high prevalence the uptake of intellectual disability services remains low among South Asian communities (Bywaters, Ali, Fazil, Wallace, & Singh, 2003) and has been attributed to culturally inappropriate services, a fear and lack of awareness of services, discriminatory attitudes among service providers, and language and communication barriers (Azmi, Hatton, Emerson, & Caine, 1997; Hatton, Azmi, Caine, & Emerson, 1998; Hatton et al., 2010; Heer, Rose, & Larkin 2012). Typically, services supporting families caring

for individuals with intellectual disabilities in the United Kingdom combine social care (usually funded by local authorities) with community health teams (usually funded by the National Health Service).

In the United Kingdom, there is a growing body of research exploring the views and experiences of ethnic minority families when trying to access intellectual disability services. Little is known about the service providers themselves and the challenges that working with cultural diversity can pose. Literature to date, looking specifically at working with cultural diversity in community intellectual disability services has employed case study designs (Hassiotis, 1996; Hepper, 1999; Summers & Jones, 2004). These previous studies revealed the challenges that cultural diversity can pose in terms of creating tensions between family responses to disability and professional concerns, as well as the difficulties that language barriers introduce when working therapeutically with clients. The studies provide some insight into the issues that intellectual disability teams face when

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working with ethnic minority groups. However, they have focused on referrals to psychological/psychiatric staff and therefore do not accurately reflect the make-up of intellectual disability services, which often involve multidisciplinary teams consisting of a variety of professionals.

Working with cultural diversity is not something that is unique to intellectual disability services but spans different service domains. In an increasingly multicultural society, the need to provide culturally sensitive services to ethnic minorities is likely to become more important. There has been an emphasis on terms such as “cultural competence,” “cultural diversity,” and “cultural awareness” within health and social care services, which have all put pressure on public bodies in terms of delivering equality and diversity in care (Tervalon, 2009). For example, documents such as the “Toolkit for Cultural Competence in Master’s and Doctoral Nursing Education” (American Association of Colleges of Nursing, 2011) and “Learning Difficulties and Ethnicity: Updating a Framework for Action” (Department of Health, 2012) in the United Kingdom, offer guidance on cultural competence. However, they provide few practical implications and skills based advice in terms of actually delivering care in clinical environments.

Using an experiential approach, the current study aimed to explore service providers’ experiences, beliefs, and feelings about working with cultural diversity, particularly in relation to South Asian families. In doing so it sought to facilitate an understanding of staff experiences and perceptions from their own perspectives in an attempt to inform policy and practice. As far as we are aware, this is one of the first studies to use such an approach to explore service providers’ experiences of providing culturally competent care within a disability-focused team. Although the research intended to provide an account of disability-focused services in the United Kingdom, the findings may have relevance for other contexts.

Method

Participants and Procedures

Service providers were recruited from National Health Service as well as private and voluntary organizations offering peripatetic and domiciliary support services to individuals with intellectual disabilities. Staff were recruited from localities with high numbers of South Asian populations.

Ethics

Full ethical approval was obtained from the relevant ethics committee, and written informed consent was provided by participants prior to data collection.

Interview Procedure

A semistructured format was used, composed of a list of open-ended questions and prompts that were based on the

following topics: direct experiences of working with South Asian families (the nature of the difficulties experienced and opportunities for learning and reflection when providing culturally competent care), training (education & training received), coping with a range of needs (cultural/ religious), and recommendations (changes to working practices and additional support/resources). Using open-ended questions and prompts allowed the researcher the flexibility to explore issues that were brought up by the participants and helped produce experiential-level data (Palmer, Larkin, De Visser, & Fadden, 2010; Tomkins, & Eatough, 2010). For example, they allowed participants to engage with the topics in terms of narrative (What happened to you?), impression (What really struck you at the time? What do you remember most now?), type (What usually happens?), imagery and metaphor (What was it like?), embodied emotion (How did you feel?), evaluation (What should be different?), and explanation (Why do you think it happened that way?).

The interviewer took care to use words that were in keeping with the participants’ discourses and regularly asked for feedback and elaboration on certain points to ensure they were fully understood. All focus group discussions were audio-taped and transcribed verbatim. Focus groups began by eliciting some basic demographic information about the service providers (e.g., age, gender, time of employment, and qualifications). In addition, ground rules were established to ensure confidentiality and mutual respect of participants.

Analysis

Focus group transcripts were analyzed using the standard framework for interpretative phenomenological analysis (IPA; Smith, Flowers, & Larkin, 2009). Additional guidelines were used to apply IPA to the analysis of group data (Palmer et al., 2010; Tomkins & Eatough, 2010). The initial stages of the analysis provided a detailed summary of the main claims and concerns expressed by participants. Following this, the researcher began to explore more interpretative understandings of the groups’ discussions. Working with the interpretations, preliminary themes were developed and written on the left hand margin of the transcripts. These steps were repeated for all five transcripts and the themes that emerged were gathered for each group. Using Microsoft Excel, the first author began to bring the themes together according to commonalities in the ideas they were depicting. This process gave rise to two superordinate themes, which are described in the Results section. Credibility of the analysis was upheld through the use of cross-checking of the analysis with secondary researchers.

Results

In total, 20 service providers each attended one of 5 focus groups. The sample consisted of 14 women and 6 men, representing a range of professions and ethnicities (see Table 1).

Table 1. Participant Details.

Category	Number of staff (<i>n</i> = 20)
Gender	
Male	6
Female	14
Occupation	
Clinical psychologist	4
Learning disability nurse ^a	8
Occupational therapist	3
Psychiatrist	2
Social worker	1
Support worker	1
Play therapist	1
Ethnicity	
White British, Scottish, or European	14
British Indian	3
British Pakistani	2
African Caribbean	1
Length of time working in learning disability services	
Less than 1 year	3
1-10 years	5
11-20 years	5
More than 20 years	7

a. Learning disability is commonly used as the preferred term for intellectual disabilities in the United Kingdom.

Table 2. Master Themes and Subthemes Reflecting Participants' Experiences of Working With South Asian Families.

Superordinate theme	Subtheme
Language as a primary barrier to therapeutic engagement	
Understanding and managing cultural difference	Frustration at barriers Struggling with engagement and progress Accepting difference Making it work Looking for a way forward

Two superordinate themes emerged, which are presented with their subthemes in Table 2.

Superordinate Theme 1: Language as a Primary Barrier to Therapeutic Engagement

When talking about the challenges of delivering culturally competent services to South Asian families, participants referred to difficulties with communication and language barriers: "I think language and communication is always a big issue" (Joanne, Group 1). Interpreters were frequently

utilized as a means of overcoming language barriers. However, there was overall consensus that the use of interpreters posed serious problems. Some of these problems were highlighted specifically by South Asian participants as they reflected on their own experiences of being bilingual. For example, one participant identified the failure of interpreting services to recognize the distinctions between different South Asian languages and complications with interpreters claiming to be proficient in more than one language: "Some of these interpreters say they're Punjabi speaking but can also understand Urdu, a bit of Hindi and something else as well, but the only language they can properly speak is [. . .]¹ Punjabi" (Imran, Group 5). Some participants described feeling powerless and out of control in being unable to assess the quality of the interpretation: "[. . .] because you're not in control of the process, you're never quite sure what the quality of the interpretation is" (Tom, Group 3). As a result, participants described having to look out for cues during consultations as indications of poor quality interpretations, such as differences in the duration of talk between the original and interpreted information, or nonverbal signs from the client, such as confusion or uncertainty.

Some participants suggested that interpreters lacked familiarity with health-related concepts and often introduced added judgments and biases into the consultation process. For one participant this raised concerns because he felt that both parties (professionals and parents) had an inadequate understanding of each others' concerns:

The way they (interpreters) ask the question to the person is completely wrong and the way they interpret something back is completely different [. . .] they're not from a healthcare background, so they end up pruning down the complexity of the responses and the questions. (Sukhdeep, Group 5).

Additionally, service providers using psychological approaches reflected on how the use of interpreters can alter the nature of the therapeutic relationship by introducing a greater potential for misinterpretations and a lack of emotional sensitivity during consultations: "The way the interpreters ask [. . .] in such a crude way and you can see the person, who's come to the appointment feeling very uncomfortable, so it's a poor experience" (Imran, Group 5). As an alternative to using interpreters, participants talked about using family members or friends or calling on bilingual colleagues. Generally siblings were the preferred means of non-professional communication with non-English speaking parents, as they were seen to provide an insight into the family, had a shared understanding of the difficulties and were likely to be fluent in English:

Sometimes you can ask family members to translate [. . .] you get very good communication and you feel you get an understanding of the situation from the family members but at the same time [. . .] they have their own agenda really. (Ben, Group 3)

Superordinate Theme 2: Understanding and Managing Cultural Difference

The second theme reflects a five-stage process in which participants described their frustrations with barriers and struggle with engagement initially. This then led to a process of reflection and attempts at trying to overcome these barriers in the form of accepting difference, making it work, and looking for a way forward.

Frustration at Barriers. A major challenge to the delivery of care was trying to work within family contexts. The family unit was seen as an important part of the caregiving process for South Asian families, because the family was seen as a source of support. However, it was evident that there were tensions between the values of “Western” services and the cultural values of South Asian families, particularly in terms of their implications for engagement: “I feel as though I’m going to have more of a battle to persuade people to accept services, the families might feel that they want to deal with the problem themselves” (Ben, Group 3). South Asian families were thought to cope with difficult and challenging behavior within the family with little help from any formal services. As a result, service providers talked about a reluctance to seek help resulting in families delaying contact with services until situations reached crisis point and could no longer be contained within the family: “The two families that I’ve worked with didn’t gain input from services until it was at crisis point and then it was like, ‘we really need help now’” (Rachael, Group 1). Containing caregiving within the family environment meant that often service providers were unaware of the needs of South Asian families and, as a result, felt helpless in terms of providing support: “[. . .] you don’t know what’s going on a lot of the time. So if you don’t know you can’t do anything” (Tom, Group 3).

Struggling With Engagement and Progress. Some groups highlighted that parental denial of the disability and stigma from within communities made it difficult to engage with families and introduce successful interventions.

In these cases, families were seen as actively seeking out professionals and alternative treatments such as healers in search of a diagnosis that negated the disability:

Imran: They won’t accept it’s a long term condition which needs long term management and with disabilities there’s lots of stigma around so you have this run for cures and faith healers.

Zara: With the family I worked with, I had to explain what the disability is and how it was going to affect the family [. . .]

It also became evident that the underlying philosophies of services could sometimes cause dilemmas for staff in everyday practice when working with South Asian families.

Principles such as individuality and choice were seen to conflict with the beliefs and values of South Asian communities. For example, in the extract below, one group explored the issues surrounding the proposed marriage of a person with intellectual disabilities:

I saw a young man and the response of the family was to get him married and for his wife to look after him and that was quite a different response to the way we would normally work. I think they then saw the services as being quite oppositional because we were tasked with the notion of asking was he able to consent to marriage? (Tom, Group 3)

This negatively affected their relationships and engagement with families. As a result, service providers feared that being viewed as “oppositional” could lead to mistrust and apprehensions about using services in the future. They also acknowledged that South Asian families may experience a degree of “loss of control”: “There is a massive loss of control, you know professionals step in and do things in the individual’s best interests” (Sukhdeep, Group 5).

Accepting Difference. Participants’ accounts of providing culturally competent care involved a significant amount of questioning, with regard to diversity and how this idea fitted into their work practices. For example, the staff acknowledged that assumptions which viewed South Asians as a homogeneous group were important in their initial thoughts: “Workers might have a bit of an assumption that cultural issues might be quite important perhaps thinking about religion or values [. . .]” (Sharon, Group 1). Simultaneously, participants talked about the heterogeneous nature of South Asian communities, which go beyond what is believed to be typical of “South Asian” culture. As one participant described, viewing South Asians as a collective group consequently overlooked intragroup variations in religious or cultural practices, thus highlighting the need for staff to challenge their assumptions: “Sometimes we focus too much on culture and not thinking about individual factors, because you can have preconceived ideas about cultures and religions but not everybody’s going to believe all those things or practice those things [. . .]” (Jane, Group 3). The complexity of managing diversity was further highlighted in an extract from Group 3 below, which demonstrates how factors such as acculturation can complicate ideas. Acculturation refers to the adjustments and changes experienced by immigrants in response to their contact with new host countries (Berry, 1997). The discussion highlights the dangers of how fixed ideas can oversimplify the experiences of South Asian families, and reiterates the importance of challenging personal assumptions:

Tom: Some things are retained in second generations, for example, I had a client, his brother was a very well educated man [. . .] and the two generations (father

and brother), had the same goal which was to get the client married off. So in some ways while the well educated brother was different he was also very much the same as his dad.

Ben: But that's about the cultural beliefs isn't it? [. . .] that sort of statement wouldn't surprise me that somebody that's been born in this country and exposed to that still has those strong cultural links.

Tom: But you might think that somebody who'd been born in the country [. . .] might be trying to persuade his dad to say "well we do it differently here," you know what I mean?

What resonates throughout the extract above is the participants' use of questioning to seek reassurance and elaboration from each other, which again illuminates the ambiguity and uncertainty around this issue of diversity.

Making It Work. All participants described having dealt with a complexity of needs, which was made harder by limited resources. As a result, they talked about having to adopt flexible approaches to providing culturally competent care: "[. . .] you know that you're going to come across barriers [. . .] but, you do strive to find different ways of doing things" (Amrit, Group 4). Often this involved adopting a "family-centered" approach. For example, some participants talked about locating the power and authority within family units to improve service delivery: "I think maybe you have to find out where the power and the authority is in the family [. . .]" (Jenny, Group 1). Other participants saw siblings as an important means of identifying the needs of the child with disabilities. For example, in the extract below one participant described working collaboratively with a client's brother in an attempt to form relationships and grasp a better understanding of the client's needs.

[. . .] with male clients in particular, I work with their brothers, because they're closer to their own generation and I actually explain to them what's going on and try to improve the bond between the two brothers [. . .]. (Amrit, Group 4)

South Asian service providers specifically described unique experiences of working with families with whom they shared the same cultural background. As illustrated in the extract below, two South Asian participants discussed their experiences of working within professional boundaries while still trying to engage in a culturally sensitive manner. This extract highlights the complexity of working with diversity and reinforces that sharing a cultural background does not simply remove the challenges to engagement:

Imran: With people from South Asian backgrounds, it's much more culturally normal to ask "which area of South Asia are you from? Are you married?" [. . .]

Sukhdeep: That's all part of engagement. I think it feels appropriate to give a little bit, just building that

relationship [. . .] I think being from a South Asian background you kind of feel it's not a problem. I think it'd be more of a problem if I didn't, it'd be rude.

Looking for a Way Forward. What became apparent through the service providers' accounts were their concerns and worries about whether they were delivering interventions in a culturally appropriate and respectful manner: "[. . .] you kind of wanna be respectful but you think "oh my gosh! I'm totally naïve about this" and you don't wanna get it wrong and say the wrong thing" (Brigid, Group 1). Most of the non-South Asian respondents revealed a reliance on the Internet as a primary resource for obtaining culture-specific information. For example, in the extract below, one participant describes using the Internet and adopting a "trial and error" method involving consultations with families to gain feedback about whether their style of service delivery was meeting the families' needs. Additionally, although most of the participants mentioned the need for training programs on cultural diversity, they highlighted that cultural identities were not fixed and consequently suggested that training programs may be limited as they tend to view South Asians as collective groups:

My first thought would be to look it up on the internet. I think there's an element of trial and error, you might go back to the family and ask if it's right and invite the family to tell you about their culture [. . .] that's more useful than a [. . .] diversity course, it's far more practical, plus every family is different and these courses don't cover for that do they? (Laura, Group 2)

Other suggestions included the use of community strategies aimed at raising awareness of intellectual disabilities and facilitating prevention through the promotion of earlier intervention. One group stressed the importance of working with faith organizations within South Asian communities and reflected on examples of where such partnerships had been successful: "You can't get to the mosque without tripping over twenty stalls of people telling you to stop smoking. We could do that for disabilities as well. [. . .]" (Imran, Group 5). Through collaborations with local communities and faith organizations there was a sense of building trust and cohesion between the community and services. This appeared to be a crucial element in improving service uptake and breaking down misconceptions and fears within the community about accessing services.

Discussion

The study provided an in-depth insight into the experiences of service providers working with cultural diversity in health and social care services. This is particularly relevant to the nursing profession and highlights the importance of enhancing cultural competency as a means of improving health outcomes for patients and removing health disparities (Department of Health, 2012; Tervalon, 2009).

Superordinate Theme 1, "Language as a Primary Barrier to Therapeutic Engagement," identified communication and language as a primary barrier to effective service delivery to South Asian families. These findings are in keeping with research into ethnic minorities, which has identified language as a common barrier to effective engagement with health and social care services (Jackson, 2007; *Katbamna*, Baker, Ahmad, Bhakta, & Parker, 2001; Owens & Randhawa, 2004; Richardson, Thomas, & Richardson, 2006). In the current study, some service providers talked about the use of family/friends for interpretation. However, according to the U.S. Department of Health and Human Services, OPHS, and Office of Minority Health (2001), this should be avoided where possible. Using untrained family members or friends for interpretations can breach confidentiality and also puts increased burdens on the individuals doing the interpreting. Currently, the National Health Service has no regulated training or requirements for interpreters. However, there is national agreement for the use of interpreters in criminal investigations and proceedings, which stipulate that interpreters should meet set standards and therefore be registered with one of the recommended registers (i.e., the National Register of Public Service Interpreters). In addition, the use of family members and friends as interpreters is not recommended and if essential they must be able to interpret at a level that is acceptable to the court.

Language barriers can lead to reduced service uptake and awareness, dissatisfaction with services, and a reduced understanding of disability (Bywaters et al., 2003; Hatton et al., 2010). Quality interpretations have been shown to promote improved congruence in beliefs and expectations about treatment, as well as ensuring diagnostic accuracy and quality of care (Farooq, Fear, & Oyeboode, 1997). However, interpretation is complex requiring interpreters to translate information immediately with little time to consider emotional issues (Tribe & Raval, 2003). Often for service providers the use of interpreters introduces a new way of working in a triad, which requires adaptation and flexibility. Training and education have been shown to effectively increase service providers' satisfaction with interpretations (Gerrish, Chau, Sobowale, & Birks, 2005; Karliner, Pérez-Stable, & Gildengorin, 2004). Simple techniques such as briefing sessions with interpreters and health professionals prior to consultations are likely to foster more collaborative and effective consultations.

As outlined in the subthemes "Struggling With Engagement and Progress" and "Frustrations at Barriers," service providers described their struggle to understand and work with cultural diversity. Key components of this were the service providers' perceptions that South Asian families prefer to provide care within family units. This notion of South Asians "caring within the family" has been challenged by recent research, which has highlighted that it is an outdated and stereotypical view (*Katbamna*, Ahmad, Bhakta, Baker, & Parker, 2004). Nonetheless, almost all the participants recognized the

importance of family care when working with South Asian communities. Interestingly, the service users (individuals with intellectual disabilities) were largely absent from the participants' narratives. This appears to go against the principles of intellectual disability services, which promote "person centered planning" where listening and responding to the service users' needs are central. This raises questions about the cultural transferability of principles such as "person centered planning" to contexts in which the family as a whole plays an integral role in the caregiving process.

Participants in the current study felt ill-equipped to explore and respond to families' cultural needs for fear of causing offense and "getting it wrong." These concerns are in keeping with other research, which has demonstrated that service providers feel ill-equipped to deal with the needs of patients from culturally diverse backgrounds and tend to rely on generalizations and stereotypes to inform the way they work (Hassiotis, 1996; Jackson, 2007, Owens & Randhawa, 2004). There appeared to be uncertainty in the way participants felt they should respond to cultural difference, which centered on whether to use a homogenous or heterogeneous approach to providing culturally competent care. A strategy of treating everyone the same tends to undermine the significance of cultural diversity and how it influences the delivery of care, and the reality of minority ethnic people's lives. This appears to be a clear challenge in developing culturally sensitive services. The study highlights the need to move beyond a reliance on expectations and assumptions and instead conduct further assessments in order to fully understand the context in which individuals and families are situated, as suggested by Heer, Larkin, and Rose (2012).

Participants talked about having to cope with the challenges of providing culturally competent care on their own, learning from experience and relying on Internet resources. This highlights the need for services to view cultural competence as a part of practice. This could be achieved by incorporating "cultural assessments" into care pathways, aimed at identifying the specific cultural needs of individuals and families. This could take the form of a simple checklist identifying areas to explore, such as levels of acculturation, cultural and religious values, and beliefs, as well as the role of the family in caregiving. Alternatively, it could involve more reflective multidisciplinary team working, which could allow service providers to make formulations and ask questions related to culture in teams. In fact one of the things that stood out about this study was the thought and effort that participants put into trying to achieve culturally competent services, as outlined in the subthemes "Accepting Difference," "Making It Work," and "Looking for a Way Forward." The group format appeared to motivate discussions, reflection, and self-appraisal to evaluate working practices in relation to ethnic minorities. The group discussions seemed to shift from problem focused talk, which focused on identifying the challenges when working with South Asian

families to solution focused talk, which focused on exploring ways of working to overcome these challenges often involving adaptability, trust, and patience. This insight could help inform future service development. By using more “experiential” approaches to dealing with cultural issues and providing culturally sensitive care, staff could learn through direct experience and reflection.

A fundamental aspect of delivering culturally competent care is working in teams that are representative of the ethnic community and are able to identify specific needs. This may involve the inclusion of South Asian representatives in consultation forums and strategic planning to give a voice to ethnic minority communities. It appears that more needs to be done in order to appropriately allow minority ethnic service users to fully participate in service design and delivery so that they do not experience a “loss of control” or dissatisfaction with services. This would require tackling barriers to service involvement including fear and lack of trust. As illustrated in the subtheme “Looking for a Way Forward,” working collaboratively with local communities including religious institutions could be a way to improve engagement with ethnic communities. This is something that has been used in the United States through Lay Health Advisors, who act as members of the local community in promoting wellness, education, and outreach work in a culturally relevant way (D’Elia, Black, Carpio, & Dwyer, 2009).

Although the study did not aim to produce findings that were generalizable, we appreciate that the experiences described are likely to include issues that are specific to staff working in intellectual disability services. Therefore, it is suggested that the findings be used as a guide. It is possible that extending the study to other cultures and different groups may have provided differing insights. The composition of the group discussions may have introduced the potential for “conflicts of interest” since most of the service providers knew each other well and their responses may have been influenced by the hierarchical nature of services. Additionally, some participants may have been reluctant to share their views in fear that they may be construed as discriminatory. Finally, there are challenges in applying IPA to group data. Group data can overemphasize the importance of the group and the group dynamics and in doing so lose the idiographic nature of IPA (Tomkins & Eatough, 2010). As a result, it is important to strike a balance between exploring collective concerns/experiences and identifying individual perspectives on these themes.

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Note

1. Ellipses [. . .] have been used to omit parts of the original extract.

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