The experiences of nurses working with people with intellectual disabilities and mental health problems.

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Aim: This study aims to explore the experiences of nurses working with people with intellectual disabilities and mental health problems. **Background:** Providing mental health care for people with intellectual disabilities is problematic and challenging. Nurses are considered central to providing mental health care for people with intellectual disabilities. However, several studies indicated nurses face critical challenges when dealing with people with intellectual disabilities and mental health problems. **Methodology:** An interpretive qualitative approach was adopted. The study employed a purposive sampling technique. Seven nurses were recruited and in-depth, unstructured interviews were conducted to collect data. The study was approved by the Ethics Review Committee of Dublin City University and the local Ethics Committee of the service where the researcher conducted the study. **Analysis:** Transcribed interviews were analysed through thematic content analysis. **Results:** The study uncovered a range of challenges for nurses in providing mental health care for people with intellectual and mental health problems. These included: lack of training and education for nurses in relation to mental health needs of people with intellectual disabilities, inability to communicate with people with intellectual disabilities and mental health problems, institutional life of people with intellectual disabilities, and lack of co-ordination of multi-disciplinary team. **Conclusion:** Literature acknowledged the need for mental health care for people with intellectual disabilities, and agreed that nurses' roles are crucial in both promoting and treating the mental health of people with intellectual disabilities. Therefore, the service providers at a local level must engage with administrators, multi-disciplinary teams, nurse managers and nurses to implement the recommendations of the study to support nurses in order to render better mental health care for people with intellectual disabilities.

Introduction

The prevalence of mental health problems in people with intellectual disabilities and in need of mental health care for them is evident from international literature (Cooper et al. 2015). Even though several professional groups such as doctors, speech therapists, and psychologists are involved in providing mental health care for people with intellectual disabilities, nurses' roles are considered vital.

Background

It is evidenced that prevalence of mental health problems among people with intellectual disabilities is significant (Holt, Hardy and Bouras 2008). The rate of mental health problems among people with intellectual disabilities exceeds that of those without intellectual disabilities (Crocker et al. 2014). Devine, Taggart and McLornian (2010) revealed a more precise and narrow margin of 20 to 50% of the hospital population with intellectual disabilities suffer from mental health problems. These people

are thus in need of mental health services (McGarry 2015). *A Vision for Change* was published in 2006 in Ireland by The Department of Health and Children. This formed the basis for Irish mental health policy, and it emphasised the importance of providing mental health services for people with intellectual disabilities in Ireland.

There are several professional groups involved in providing mental health services for people with intellectual disabilities: doctors, occupational therapists, speech and language therapists, behavioural therapists, physiotherapists and nutritionist. But nurses are considered central to providing mental health care for people with intellectual disabilities because they work closely with them on a daily basis (Holt, Hardy and Bouras 2008). In addition, nurses provide intimate care; therefore nurses are in a position to build good professional relationship with people with intellectual disabilities (Holt, Hardy and Bouras 2008).

Hagan and Thompson (2014) argued that communication skills and therapeutic relationships are essential elements for mental health practice through person-centred approach. Muir et al. (2015) identified that many nurses find it difficult to establish communication and maintain therapeutic relationships with people with intellectual disabilities. This makes it difficult for nurses to identify and meet the mental health needs of people with intellectual disabilities (Goldbart, Chadwick and Buell 2014). In addition, the introduction of the theory of normalisation underpinned by the principles of integration (Clegg et al. 2008); social inclusion (Whitehurst 2006); choice and rights (Smyth and Bell 2006) has increased the needs and demands of people with intellectual disabilities. Consequently, people with intellectual disabilities have a right to access and choose between various mental health services which has been given greater recognition (Priest and Gibbs 2004). The theory of normalisation led to nurses' roles and responsibilities undergoing tremendous change from traditional residential care to comprehensive person-centred care (Jingree 2015).

Pridding, Watkins and Happell (2007) identified the need for further studies in the area of intellectual disabilities and mental health problems to provide better mental health services for those suffering with intellectual disabilities and mental health problems. In Ireland, Sheerin and McConkey (2008); Sheerin (2008) recommended further research to shed an understanding on the experiences and roles of nurses who are working in residential intellectual disability settings.

Methodology

Design

Interpretive qualitative research was used in this study due to its ability to uncover meanings, beliefs, perceptions and care management experiences of the participants (Silverman 2000). While, Popay and Williams (1998) indicated that a qualitative study fully focuses on the meanings that people give to their experiences; it allows the researcher to find a relationship between knowledge, experience, action and the social factors that influence these processes. Moreover, a qualitative study helps the researcher to obtain a comprehensive summary of participants' experiences in their everyday language (Johnson and Waterfield 2004).

Sample and Recruitment

This study employed a purposive sampling on the basis that the participants have experiences of working with people with intellectual disabilities and mental health problems. Gerrish and Lacey (2006) noted that purposive sampling is frequently used in qualitative research studies to describe the experiences of participants. The participants are selected on the basis that they have first-hand experience. The nurses were required to have a minimum of one year experience in working with people with intellectual disabilities and mental health problems.

The clinical nurse managers of each unit which provided mental health care for people with intellectual disabilities was contacted and permission was obtained to place the study advertisement in their staff notice board. Prospective participants were asked to return the study invitation card with reply envelope provided through the hospital internal mail. In total, seven participants indicated their willingness to participate: five from one service and two from another service. I approached each respondent through their chosen medium of contact and arranged a meeting at a time and place convenient to them. At the initial meeting, I offered further clarifications about the study and checked their eligibility to take part in the study. We then organised a time and place for the interview.

Data Collection

In this study, I used in-depth, unstructured one-to-one interview as a primary method of data collection to answer the research question. Robinson (2000) observed that the in-depth nature of the interview provides an opportunity for the researcher to link all the information provided by the participants. Power (2008) pointed out that the researcher can fully examine each participant's experiences, feelings and opinions, which are relevant to the research purpose through in-depth interviews. While, Speziale and Carpenter (2003) suggested that an unstructured interview provides a freedom for participants to expand upon and to express their experiences.

I conducted seven interviews in total to collect information for the study: 5 Irish nurses and 2 Asian nurses. The interviews were conducted over a month. Individual in-depth, unstructured interviews were conducted with each participant in a time and place convenient to the participant. Out of seven interviews, one interview was held in the participant's own home, two interviews were held in participants' cars and the remaining four interviews were conducted within the hospital grounds. Data collection was commenced with a broad opening question: "Can you please tell me about your experience of working with people with intellectual disability and mental health problems?". In addition, during the interview I asked exploratory questions: "can you add more about that?" and "how did you feel about that?" to gain full understanding of their perceptions. I used a small digital voice recorder to capture the interviews because digital recorders have a higher signal-to-noise ratio than traditional recorders.

Data Analysis

I visited and re-visited the transcribed interviews several times to familiarise myself with the participants' experiences. I used thematic content analysis as advocated by Silverman (2000) to detect the themes and sub-themes that were hidden in the data. I created a brief summary of analysis of each participant's interview, which was helpful to identify the key points as well as to understand the participant's experiences. Finally, the true meaning of the themes was checked with some participants who verified my findings.

Trustworthiness of Data

In order to establish trustworthiness of the study, I met with my supervisor periodically throughout the research process to discuss and agree with the development of the analysis process. A random selection of the interview transcripts were also analysed and the initial coding and final themes were agreed by me and supervisor.

Ethical Consideration

The study was approved by the Ethics Advisory Committee (EAC) of School of Nursing, Dublin City University, the Ethics Committee of Dublin City University and the Intellectual Disability Services where I conducted the study. Prior to commencing each interview I gave a plain language statement and offered verbal clarification to all participants about the nature and purpose of the study. I also discussed a possible benefit of the study. In addition, I informed the participants of their right to withdraw from the study at any stage without affecting their anonymity. All participants signed the consent form before

commencing the interviews. I assured the participants that their names or details would not be used during or after the study is completed. I removed personal details from the data and assigned pseudonyms.

Results

In total seven semi-structured interviews were conducted in the study. Their experiences of providing mental health care for people with intellectual disabilities were ranging from 5 to 17 years. The data analysis revealed four themes as final products. The first theme "professional up-skill" explores the importance of education and in-service to health care professionals in relation to manifestation and presentation of mental health symptoms among people with intellectual disabilities. The second theme, "assessment and diagnosis" describes the difficulties of nurses in identifying mental health symptoms among people with intellectual disabilities. The third theme, "communication" narrates the difficulties of professionals in engaging and communicating with people with intellectual disabilities and mental health problems. The final theme, "environment" illustrates the importance of safe and therapeutic environment required for people with intellectual disabilities and mental health problems.

Theme1: Professional Upskill

Throughout the interviews the participant nurses revealed that they are in need of short-term in-service training and formal post graduate education in relation to mental health issues of people with intellectual disabilities in order to provide better mental health care. The majority of the participants felt that intellectual disabilities services should examine training needs of nurses who are working with people with intellectual disabilities, with emphasis on providing in-service training.

One participant, Siva, suggested:

There is a problem in point of view that the ID nursing point of view. We don't have ongoing training in mental health issues. Actually there should be a package developed, presented. I feel ID nurses need more specific training around mental health and mental health issues and I certainly feel that we need to become leaded.

Siva indicated that it is problematic for him to provide mental health care for people with intellectual disabilities due to inadequate ongoing mental health training. Further, Siva suggested a mental health package be developed and presented to nurses who are working with people with intellectual disabilities and mental health problems.

Ram agreed with Siva:

I like to have that kind of programmes which will focus on clients with ID and mental health problems, that'll be very helpful to bring out and like say to work efficiently in the field of ID and mental health problems (Ram).

Ram indicated that an in-service programme which covers mental health issues of people with intellectual disabilities would help nurses to provide efficient mental health care for people with intellectual disabilities.

Guru stated that

The area you trained in, my area of training is mental health, so you have your skills in mental health but in ID your skills probably severely lacking. However, it is through working with people with ID you will get a better picture but in training point of view, there is severely under lacking, because of lack of available courses for nurses. So they have to train the nurses who are working with people with intellectual disabilities. More in-service training needed on site (Guru).

Guru pointed out that skills are developed through working with people with intellectual disabilities; however Guru would like to see in-service training on site for nurses.

It was expressed by Guru that nurses who are working with people with intellectual disabilities need a post-

graduate education in the area of mental health and intellectual disabilities in order to meet mental health needs of people with intellectual disabilities;

In my personal point of view any nurses who are not trained in that area to get some form of basic training with in ID through in-service training it is way forward but it allow the nurses to work with people with ID even the general, paediatric nursing to do some kind of post graduate course. (Guru)

In addition, Guru stated the importance of providing education for nurses:

No matter what course you are doing, you may get the basic concept but enable the nurse to provide better care you have to do post graduate course (Guru).

Guru articulated that nurses need a post graduate course irrespective of their previous training in order to provide better mental health care.

Theme 2: Assessment and Diagnosis

The participants indicated that assessment of mental health symptoms in people with intellectual disabilities is difficult. They suggested that presentation of mental health symptoms in people with intellectual disabilities is different to symptoms of people with average intellectual levels. The majority of the participants stated that identifying mental health symptoms in people with intellectual disabilities is troublesome and complex.

Siva suggested that

People believe that the presentation of mental health symptoms in people with ID is different (Siva).

Siva recounted on his experience:

That was the problems we really suffer and we should be more intuitive awareness. Then we hand it over to psychiatrist.

Another nurse, Sakthi, revealed his experience of finding symptoms in people with intellectual disabilities:

you know somebody with a bipolar disorder yeah, it can take several years for the person to be diagnosed and we actually do it again because we have an disability its even harder because it manifest itself sometimes as a challenging behaviour he pretend to medicate to reduce the challenging behaviour they actually taking into what's causing the challenging behaviour (Sakthi).

Meenakshi recalled her experience of finding mental health symptoms:

Its actually is quite difficult I think, as an intellectual disability nurse or a mental health nurse actually determining whether somebody with an intellectual disability has a mental health problem because it can be difficult to say whether is it a behaviour? Or Institutional behaviour? Or a learned behaviour or a Genuine mental health problem.(Meenakshi)

From the above statements it is clear that nurses struggle to distinguish mental health problems from challenging behaviour in people with intellectual disabilities. This causes delay in recognising mental health symptoms and an expert mental health inputs. The participants indicated that they do not use any assessment systems or tools to assess mental health symptoms in people with intellectual disabilities. In addition, these nurses are not even trained to use any assessment tools as they are only used by psychiatrists or psychologists.

Siva spoke of his experience:

Many times we didn't use any formal mental health assessment unless the psychiatrist actually initiates it….still on many units don't have mental health assessment available. They also don't have training to do it (Siva).

While Ram said:

There is no assessment tool to assess them. To my knowledge and experience I couldn't see any exact tools which they can distinguish a person who has ID and mental health problems.

These nurses agreed that they need a specific tool to mark symptoms of mental health in people with intellectual disabilities. In addition, training in relation to using the assessment tool was necessary if these nurses are to make clinical decision about their clients. Ram indicated a lack of awareness of the availability of assessment tools to assess mental health symptoms in people with intellectual disabilities. This led to difficulties in assessing mental health symptoms in people with intellectual disabilities because of unavailability of suitable assessment tools.

Theme: 3 Communication

The participants revealed that role and contribution of a multi-disciplinary team is essential in providing proper mental health services for people with intellectual disabilities. In addition, the participants agreed that they need assistance from a multi-disciplinary team and they believe that the multi-disciplinary team must be fully functioning in order to help nurses to meet the mental health needs of people with intellectual disabilities. However, it has been identified from the participants' information that there are different views among nurses about working relationships with multi-disciplinary team and this theme recurred throughout the interviews.

On the relationship with multi-disciplinary teams, Siva remembered:

Overall my experiences have been quite positive because I am working in the service where the multi-disciplinary team seems quite strong and I have to say I felt we gave good input.

Siva revealed that the relationship with multi-disciplinary team is quite strong and easy.

In contrast, Ram commented:

Multi-disciplinary team is way away from the front line staff. Like say, for example like say they don't co-ordinate with the key worker and plan the programmes or plan the activities what we or plan the therapies what we have to follow. We are just told the instructions after all the thing is planned because being a nurse I am the key worker, If I am a key worker for a client, I am not included in that discussion rather than the managerial level and the behaviour therapist or like who all is going to co-ordinate that programme is taking part in that then the key worker is not invited or consulted with what is going to happen.

Further, he explained:

I feel like say we are only told like say ok this is the plan A,B,C…… and to carry out the plan'. So In that way I feel like you can't express your own willingness or your own wish or your own ideas, 'Alright' ….. even though like if it is evidence based, you can't express your own ideas, because they say you are a frontline staff, So in that way I feel there's a bit of friction while getting with the MDT.

It has been demonstrated by Ram that the relationship with a multi-disciplinary team is difficult, so it thus sometimes creates friction among professionals. Further Ram felt that nurses are simply being asked by multi-disciplinary team members to carry out certain therapeutic activities for clients without even being consulted by a key worker.

This study clearly identifies the relationship with multi-disciplinary teams as being an integral part of providing mental health care for people with intellectual disabilities. The majority of the participants felt the relationship with multi-disciplinary teams impacted the mental health care that is provided for people with intellectual disabilities. Many participants acknowledged that making a relationship with and co-ordinating a multi-disciplinary team is straightforward and effortless. However, Ram admitted that multi-disciplinary team members never asked his opinion or views in making a therapeutic plan for clients, but Ram was asked to execute the plan, which was made by a multi-disciplinary team member. Ram wants the multi-disciplinary team to consult with client's key worker, who knows exactly what client's abilities and needs are, before any plan is put in place for a client.

It is important to note from the participants' information that nurses recognised the value of

establishing and maintaining communication with people with intellectual disabilities.They also acknowledged that communication is important to initiating rapport and essential to providing better mental health care. This is one of many themes which evolved throughout the interviews and the most of the participants accepted that establishing and maintaining communication and relationship with people with intellectual disabilities is difficult and needs special skills. Moreover, they accepted that this can partially be achieved through experience working with this population.

Sakthi revealed his experience of using different strategies of communicating with people with intellectual disabilities:

We might have the spoken word which they can't understand what you are saying put it up on a chart up in the wall. positive reinforcement, behaviour and different programs like that, so, you know my experience with people with ID in communication would be that everybody are individualised and you cannot speak or talk to anyone person in a there can be one as two… Communicate to people with ID. Everybody is much individualised and I found that truth 15yrs I've been nurse in that. everybody is individual, you treat him that way, you communicate that way to them (Sakthi).

Sakthi also stated:

…. Inability to communicate with people with intellectual disabilities may mask the symptoms of mental health problems (Sakthi).

Ram recounted his experience:

I am working on an Intellectual disability side, I totally focus on the Intellectual Disability side. So I consider him whatever the things he is saying to me during the communication, the rapport, I think even it may be manipulative or it may be reciprocative at time. I think that's because of this intellectual level not because of the mental health problems that's the way I think (Ram).

It has been recognised by the participants that they always focus on the intellectual disability side of an individual client rather than examining the client's mental health needs. This may lead to misinterpretation or under-diagnosis of mental health symptoms in people with intellectual disabilities.

In addition, Ganesh remarked on his experience in communicating with people with intellectual disabilities and mental health problems:

we in a lot of the times working with people they don't have communication skills, so its more than technical kind of thing to lot of thing you have to go through everything and see, find your patterns you have to put to work at it, its probably more work to get the diagnosis. it's the communication thing is the hardest thing, you know (Ganesh).

It is important to note that nurses find it difficult to communicate with people with intellectual disabilities, even though they work with them every day. Further, they believed that nurses must establish a pattern of communication strategy generally to establish a relationship and more importantly to diagnose mental health problems.

Meanwhile, Meenakshi suggested:

I think educating yourself on no one that people with intellectual disability do tend to suffer mental health problems than the normal population. Its always a good starting point so that you know that the conversation might be bizarre and a little bit strange you might think maybe its not just because they've got intellectual disability, maybe you start thinking, its because of something else going on at the background and but I think developing therapeutic relationship is never been a problem to me (Meenakshi)

It is clear from this study that establishing and maintaining therapeutic relationships with people with intellectual disabilities and mental health problems plays a central role in providing mental health care for these people. The participants' experiences and reasoned that emotional immaturity

and poor cognitive and developmental disabilities in people with intellectual disabilities make it difficult for carers to establish and maintain therapeutic relationships. However, this study revealed that while a few participants have no problems in establishing communication with people with intellectual disabilities due to their level of working experience many of the participants do have problems in communicating with people with intellectual disabilities.

Theme: 4 Environment

The participants claimed that the institutional model of care for people with intellectual disabilities is out of date and provides no scope for rehabilitation and socialisation. They also felt that the service provision for people with intellectual disabilities is inappropriate to the needs of clients.

Siva commented:

I had to accept the facts that it was in an institutional kind of environment rather than in a community around and that is something that I believe the services have got to change with (Siva).

Jothi claimed:

Really I am concerned about the place the people they live in you know…. It is very sad you know (Jothi)

Ram commented on his experience:

You see the facilities of the service, it's totally back dated which can't give the client a full freedom or liberalisation or a good recreation activities or a good rehabilitation activities. It's just totally backdated and it's totally institution.

The participants revealed that the current living situation in institutions does not help people with intellectual disabilities and mental health problems. Siva believed that service provision for people with intellectual disabilities must change from an institutional model to a community model.

Nurses in this study revealed that working with people with intellectual disabilities and mental health problems is enjoyable and they feel happy. However, they expressed that they are stressed out, feel burnt-out and their working situation is challenging.

Ram suggested:

I enjoy *working with people with intellectual disabilities. I think the hardest thing to deal with is the fact that we run institutional model.*

Siva remarked:

I think the largest stress actually is working in a system that actually doesn't do anything for this people and I think that I did reach a stage where I did burn out other wise I enjoy working with them.

Jothi commented on his experience:

It's really challenging in an institution you know. Because you have to worry about your own security you know… because you wouldn't know what will happen (Jothi)

From the above statements it is clear that the participants are happy and enjoy working with people with intellectual disabilities and mental health problems. However, they concerned about their working environment where there is no significant improvement for their clients.

Discussion

It is suggested by Holt, Hardy and Bouras (2008)) that providing appropriate training and education for nurses is essential to meet the mental health needs of people with intellectual disabilities. This is also reflected in the Mental Health Commission (2009). Participants pointed to a need for in-service training which focuses on mental health issues of people with intellectual disabilities. This would equip nurses to provide better health care (Bouras and Holt 2009). Further, Bouras and Holt (2009) pointed out that in-service training for nurses is essential to promote their understanding and builds confidence when dealing with intellectual disabilities who has mental health problems. Eventually, nurses would be able to deliver and promote mental health care for people

with intellectual disabilities (Werner and Stawski 2012). Clayton et al. (2008) argued for the need of imparting necessary knowledge and skills for professionals who are working with people with intellectual disabilities, this provides greater confidence in nurses to manage people with intellectual disabilities and mental health problems.

Assessing and diagnosing mental health symptoms in people with intellectual disabilities is difficult and problematic due to their complex problems such as visual and hearing impairments (Gates 2007), poor cognitive ability and lack of capacity to communicate (Gates 2007). Throughout the interviews participants expressed the difficulty of identifying mental health symptoms and utilisation of assessment tools in people with intellectual disabilities. Further, identification of mental illness in this population is compounded by other forms of disabilities such as hearing difficulties, visual impairments, epilepsy (Gates, 2007 and Raghavan and Patel, 2005). Felstrom et al. (2005); Holt, Hardy and Bouras (2008) and Williams and Heslop (2005) have acknowledged various reasons for delays in identifying mental health symptoms in people with intellectual disabilities: lack of knowledge of nurses in using assessment tools, impairments of communication skills of people with intellectual disabilities and inadequate experience as to how mental health symptoms manifest in people with intellectual disabilities.

Raghavan and Patel (2005) and Bates, Priest and Gibbs (2004) pointed out that PAS-ADD (Psychiatric Assessment Schedule for Adults with Developmental Disabilities) and mini PAS-ADD are considered to be valuable and reliable tools and these tools are worded in everyday language. Therefore, nurses can use them to diagnose mental health symptoms in people with intellectual disabilities (Williams and Heslop, 2005; Raghavan and Patel, 2005).

The difficulties involved in communicating with people with intellectual disabilities, together with co-ordinating and communicating with multi-disciplinary team make difficult for nurses to render effective mental health services for people with intellectual disabilities (Pridding, Watkins and Happell 2007; Rask and Brunt 2007). Multi-disciplinary team's input and their relationship with carers is reflected in the literature (Minshawi 2015). The involvement of multi-disciplinary teams is an essential element of providing and maintaining mental health care for people with intellectual disabilities.

It has been found by Chambers (2003) that communication is a functional behaviour in people with people with intellectual disabilities, which helps in forming and maintaining relationships, obtaining information, providing information and social expression. However, Noens and Berckelaer-Onnes (2004) noted that communicative disability in people with intellectual disability makes them vulnerable to abuse which may cause mental health problems and hinders daily living, leading to an inability to express their mental health needs. Therefore, Firth (2009) stressed that establishing relationships is essential to making changes and providing comprehensive mental health care for people with intellectual disabilities.

Clegg et al. (2008) advocated that people with intellectual disabilities have the same rights as everybody else as to live in community. As such, service delivery for people with intellectual disabilities must be focused on a community model rather than an institutional model. It is has been identified by Bouras and Holt (2007) that a good working environment helps nurses to provide effective mental health care for people with intellectual disabilities and increases working morale among nurses. In addition, a high standard therapeutic environment supports both nurses and clients in creating a good relationship (Sturmey 2005).

Nurses in this study revealed that working with people with intellectual disabilities and mental health problems is enjoyable and they feel happy. However, they expressed that they are stressed out, feel burnt-out and their working situation is challenging (Rose, Rose and Kent 2012). Finally, Scheirs et al. (2012) stated that an inappropriate service setting for people with intellectual disabilities is a main source for unnecessary restraint and seclusion practices, which

causes mental distress and low working morale among nurses.

Limitation

The findings need to be considered against the following limitations. Firstly this study was conducted in two service location with seven participants. Secondly, the outcome of the study is drawn from individual experiences and beliefs of nurses who are providing mental health care for people with intellectual disabilities. Therefore, it is necessary to note that the findings of the study cannot be generalisable to a wider context. However, this is an important study which explores the experiences of nurses in providing mental health care for people with intellectual disabilities. This will help the service provider to plan and execute appropriate support for nurses who are currently providing mental health care for people with intellectual disabilities.

Conclusion

This study has pointed out several key issues which needed to be addressed from nurses' perspectives in order to provide better mental health care for people with intellectual disabilities. As discussed earlier professional upskill, communication, multi-disciplinary approach and place of living are the key areas to provide reasonable standard of mental health care for people with intellectual disabilities.

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