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Exploring the experiences of young people with multiplicity

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Many people view themselves and the concept of ‘self’ as singular; that is, that we are one’s self. Whilst we may use language to reflect inconsistencies in our experience of ‘self’ over time, such as “part of me felt…”, “out of character”, “back then I would have…”, our sense of a reasonably consistent singular self remains whole. Within Western linear frameworks for understanding the developing dynamic self, such as psychoanalysis, there has been an emphasis on the ‘healthy self’ being integrated and whole. This means many therapeutic approaches have focused upon facilitating trauma histories to become coherent narratives (e.g. Herman, 1992; Lifton, 1988), which can be a helpful approach for many as part of phased psychological support (e.g. ISSTD, 2011). However, some people have a different experience of identity construction (see Stocks, 2017), experiencing themselves as multiple – having more than one self in the mind and body. Ribáry et al. (2017) suggests the experience of multiplicity is best understood on a continuum between “identity disturbance” and “dissociative identity disorder (DID)” (p. 938). Ribáry and colleagues found most people who operated as ‘systems’ of selves functioned fairly well in day-to-day life, although recognised much more research is needed.

There is particularly scarce research with young people who identify as multiple outside of a diagnostic conceptualisation of what being multiple means for the individual system. This is concerning as prevalence rates for DID appear to be higher amongst adolescents in hospital settings (Şar et al., 2007; 2014), so we might hypothesise that prevalence of multiplicity would also be higher in the community for young people. Additionally, qualitative research with people with lived experience has indicated that many people first experience multiplicity in their adolescence (e.g. Parry, Lloyd & Simpson, 2018), highlighting the need for further research with young people who experience themselves as multiple.

In February 2021, we conducted an online consultation with young people who have personal experiences of multiplicity in preparation for an upcoming PhD research study. Support networks and professionals who have engaged with people who have experiences of multiplicity were also included. The consultation explored the current understanding of the experience of multiplicity and how the multiple community hopes support and understanding can be improved. The consultation included five open questions, which allowed responders to reflect on their own experiences, whether personal or professional. Overall, 94 responses were collected over a period of two weeks, showing the demand from the community to share their experiences without fear of judgement. The consultation highlighted the large supportive online network that currently exists for the multiplicity community to discuss and explore their experiences within a safe environment.

The key messages from the consultation were that the current system does not work for the multiplicity community:

- there is a current lack of understanding regarding multiplicity, particularly for young people who do not associate their experience of multiplicity with a trauma history;
- that people in the community want to be involved in research and practice decisions; and
- the language currently used is not appropriate and is seen as a barrier to support.

The current system doesn’t work

Young people told us that the current system surrounding DID/ other specified dissociative disorder (OSDD) being the focus within mental health support is not adequate or appropriate for those who do not feel they fit within the diagnostic criteria used. These diagnostic terms are also synonymous with the experience of ‘disorder’ or ‘distress’, which was not always seen as relevant for the respondents. Personal experiences shared by respondents highlighted one focus of therapeutic intervention which currently aims to integrate the different ‘headmates’ (parts of the system). However, multiples do not believe this is appropriate and instead wish to work towards positive communication with their headmates. This more holistic and accepting approach to working with multiple systems is discussed in Stocks (2007). Young people identifying as multiple do not see integration as an achievable or desirable option and instead feel it may result in people keeping their experiences secret and being unable to access support. They reported there is a disconnect between the individual’s wishes and how mental health interventions currently view the experiences – i.e. silencing through treatment and a desire to ‘fix’, rather than accept. Respondents discussed the effect of this treatment ethos as minimising their experience and expertise in self-management. This may be one way in which a community sample of young people identifying as multiple may differ to a sample of people who have struggled greatly within clinical settings with DID (e.g. Parry, Lloyd & Simpson 2017).

Multiples discussed various areas where they felt the current system is not appropriate, including professionals requesting they prove their multiplicity, which is seen to be “damaging” and “exclusionist” to many. Many respondents discussed the concealment of their experiences being linked to survival instincts, thus they may not have the language or understanding to express their experiences, especially at an early age.

As a result of the current lack of understanding and support available for people who have experiences of multiplicity, many people within the community shared their fear of being stigmatised if they were to disclose their experiences. Allowing the experiences to become normalised could facilitate help-seeking and self-acceptance due to a reduction in internalised stigmatisation. Often, people are scared of things that they do not understand. A reduction in stigma will allow people in the multiplicity community to feel accepted. Disseminating the findings of future research to the wider population as well as through policy and practice will be important to alter public perception and enhance a more nuanced understanding of multiplicity.

Not all multiplicity is based in trauma

Respondents discussed that there is a lack of understanding regarding how multiplicity develops without a basis in trauma. For respondents who did not have a trauma history, they described feeling “left out of the conversation” and “unable to access support” or resources. Many people discussed multiplicity in terms of being an experience and a part of their lives, rather than being a ‘disorder’, which needs to be treated or cured. Respondents highlighted the need within medical settings to be “suffering to be seen as valid”, which “discredits” and “invalidates” their experiences. People mentioned they may lack what is seen as traditional suffering, having experiences of multiplicity still impacts their psychosocial functioning and their day to day living, but this is overlooked currently. A greater level of understanding and resources were mentioned as currently lacking within both research and practice. Having easy to understand resources concerning multiplicity would allow both professionals and support networks to have a clearer understanding of the experiences. Respondents also mentioned having such information would allow them to feel comfortable talking about their experiences with other people. Therefore, finding a balance between trauma-informed approaches without treatment being automatically trauma focused seems an important development for support.

“Nothing about us without us”

Young people discussed lots of areas of their lives and experiences that are misunderstood or taken out of context, which was linked to the lack of co-production between experts by experience and professionals. Respondents relayed that people with multiplicity are often told information or given interpretations based on outsider perspectives, which minimises their own voices and often does not accurately portray how the experiences impact on their psychosocial functioning and day-to-day life, both positively and negatively. Ensuring multiples are centred within future research and allowing their voices to be weighed more heavily will ensure their true experiences are shared and support is developed as a result, which would address the needs of the community.

Respondents discussed the need for people who experience multiplicity to be at the centre of research and allow professionals and support networks to take a complementary role. Young people felt singlets (non-multiples) sometimes “refuse to listen” and try to “erase those who do not fit into pre-existing narratives”, which has left them feeling “uncomfortable” and “invalidated”. One young person felt they had to “pretend to be singlet” due to their experiences being ignored. Respondents discussed professionals often feeling the experiences need to be cured, instead of seeing them as a part of people’s experience. Allowing multiples to share their own experiences and be centred within research and practice will provide much needed support and understanding.

Simple steps that can be used to ensure all voices are heard include allowing everyone within the body the space to share their own experiences. Traditionally within research there is one survey to complete, or one opportunity to attend an interview, which disregards the wide range of experiences people within the body can experience. Not every headmate may wish to take part but having the option to choose is an important step towards allowing a true understanding of the experiences to emerge within research and practice. Without having the ability to share all experiences, research remains ableist and exclusionary to the community it hopes to centre and support. Therefore, research with people identifying as multiple may need to be more flexible in terms of providing a variety of platforms and time points for headmates to take part in a comfortable way. During interviews with the central persona in particular, careful consideration should be given to how to obtain informed consent from the system and which headmates may wish to opt-out of research. This could be navigated through conversation prior to research activity taking place.

Language

Respondents discussed feelings of “hurt” and “discouragement” when certain terminology is used. People also related the connotations of certain terms to the wide spectrum of multiplicity, which includes Dissociative Identity Disorder, Other Specified Dissociative Disorders, voice hearing and positive multiplicity. By ensuring accurate language is used for the various experiences, it will become clear how varied individuals’ experiences are, and thus the support available can be tailored and improved. The medicalised language used to describe multiplicity was said to be a barrier to accessing support and information for many people. While traditional language such as ‘parts’ or ‘alters’ may be beneficial or appropriate choices within specific groups such as adult peer-support services, young people who responded to the consultation found them to be non-inclusive and ingrained within medical assumptions which do not reflect their experiences. They also discussed feeling a stigma attached to this language, echoed within the media, which is harmful to people with experiences of multiplicity. Often the focus of TV shows and films portray a negative stereotype of people with “unusual” experiences, thus the language utilised in the media is associated with negative understanding.

Respondents shared various positive terms which they prefer, including “system”, “headmate”, “system members”, and “plurals”. Utilising preferred language, as is true with other areas of mental health research and practice, allows the individual to feel supported, included and visible. Along with allowing experts by experience to choose their preferred language to discuss their experiences, allowing headmates to be addressed using their chosen pronouns and names was discussed by many people during the consultation. These may be different for each headmate, or the system may have a system name which they wish to use which incorporates all within the body. Ensuring inclusive, non-ableist language is utilised humanises and normalises the experiences, which is the main hope for many young people in the multiplicity community. Each headmate has their own experiences, memories, emotions and requirements, thus should be spoken to and referred to in their own preferred way. Asking questions as to preferred pronouns and language choices prior to research activities with young people identifying as multiple could ensure suitable linguistic terms are used, nurturing the working alliance and positive research engagement for all.

Next steps

Over the next three years, we will be undertaking iterative research with young people who identify as multiple to develop a conceptual model of multiplicity built with experts by experience. This short consultation process has demonstrated that many young people who identify as multiple do not currently feel as though they have suitable access to relevant support and resources. This research could address this, as well as informing the developing literature base in relation to a nuanced and holistic understanding of the aetiological and experiential phenomena associated with multiplicity for young people.

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