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# “It’s not like you have PTSD with a touch of dissociation”: Insights into Dissociative Identity Disorder through First Person Accounts

**Authors:** 1) Dr Sarah Parry, corresponding author [s.parry@mmu.ac.uk](mailto:s.parry@mmu.ac.uk); 2) Dr Mike Lloyd; 3) Dr Jane Simpson

1 Department of Psychology, 3.11 Brooks Building, Manchester Metropolitan University, Manchester, M15 6GX, UK

2 Vale House Resource Centre, High St, Winsford CW7 2AS3

3 Division of Health Research Faculty of Health and Medicine, C39Furness College, Lancaster University, Lancaster, LA1 4YG

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### Abstract

**Purpose.** Five participants with diagnoses of dissociative identity disorder offered to discuss their experiences, to provide new insights and understanding around their condition, which is often misinterpreted, misunderstood and mistreated.

**Procedures.** Through an interpretative and idiographic analysis of first person accounts, three themes emerged to capture the experiences shared by participants.

**Main findings.** Firstly, *recognising who I am and when I am in time* discusses the difficulties in locating and finding stability for the central persona in terms of time perception. Secondly, *understanding the needs of the internal system* connects experiences of dissociation to emotional regulation and relational difficulties, which were reported across the accounts. Thirdly, *trying to help others understand what the self doesn't always fully understand* explores the complex process of facing unusual experiences and then trying to foster understanding with healthcare professionals.

**Principal conclusions.** The participants' accounts indicate that their alter parts have specific life times and as such some younger parts are often not aware of key life events or strengths of the adult parts. Most of the participants reported benefitting from psychological or psychiatric support at times, although experienced many relational challenges and struggled to articulate important information about their unique conditions during times of crisis, which was often when participants were invited to share information. Eight recommendations for practitioners emerged from the analysis.

**Keywords:** dissociation, dissociative identity disorder, memory, interpretative phenomenology

## **“It’s not like you have PTSD with a touch of dissociation”: Understanding Dissociative Identity Disorder through First Person Accounts**

### **1. Introduction**

Dissociation can be understood as a disconnection or psychological absence from an experience or the self (British Psychological Society [BPS], 2014a). It is thought that dissociation as a coping mechanism develops due to unbearable experiences, usually with an attachment figure in childhood, that are too overwhelming to be managed through only one self (Dalenberg et al., 2012; Schimmenti & Caretti, 2014). Dissociative experiences can be considered on a continuum (BPS, 2014a; Braun, 1988), which suggests dissociation ranges from day-dreaming and momentary disconnectedness through to moderate to high levels of dissociation including derealisation, depersonalisation and dissociative identity disorder (DID).

The construct, appearance and origins of DID in particular have been fiercely debated, although a seminal review concluded the diagnosis: “meets accepted standards for content, criterion and construct validity” (Dorahy et al., 2014, pp. 407). DID is thought to affect 0.5% to 5% of the general population, although there is great variation across cultures (Castillo, 1997; Slogar, 2011) and the varying methods of assessment are likely to influence these statistics (see Dorahy et al., 2014). Gender differences have also been found, with women being nine times more likely to receive the diagnosis than men (Lewis-Hall, Williams, Panetta, & Herrera, 2002). Although empirical evidence suggests men are just as likely as women to experience dissociation (Sar, et al., 2014), due to socio-cultural factors (Spitzer & Freyberger, 2008), men are less likely to receive a diagnosis or a dissociative disorder (Shevlin, Murphy, & Read, 2015).

Several prominent theories attempt to explain the epidemiology of DID, which is generally understood to be a complex and long-term response to an attachment based trauma, such as neglect and abuse, often during the early years of life when children have little autonomy or power (Herman, 1992; Nijenhuis & Van der Hart, 1999; Petersen, Joseph, & Feit, 2014). One such theory proposes structural dissociation, which suggests a division occurs in one’s personality (Van der Hart, Nijenhuis, & Steele, 2005; Nijenhuis, & Van der Hart, 2011). Thereafter, divided parts of the person can be familiar or unknown to the central personality and are usually referred to as parts, alters, self-states or personas; although these

terms can hold different personal meanings and people with dissociation often specify the term that most befits their unique experiences (Meyer, 2011; Parry, Lloyd & Simpson, 2017). The concept of structural dissociation is similar to that of compartmentalisation dissociation (see Brown, 2006; Holmes et al., 2005).

Offering a practitioner and dynamic perspective, Lesley and Varvin (2016) propose further critical consideration of the theory of structural dissociation and the individuality of experiences of DID. Importantly, they draw attention to the individual pre-trauma and relational factors that influence a person's sense of self and experience of their internal working model. Of particular relevance to healthcare providers, Lesley and Varvin (2016) consider how pre-trauma relational patterns influence how a person might respond when shaken by trauma, and how a combination of experiences might dictate engagement patterns with new attachment figures thereafter, such as through a therapeutic relationship. In this way, a person's relational patterns and life experiences around the trauma are considered in relation to the development of inner fragmentation, rather than identifying the trauma as the isolated catalyst to trigger the emergence of separated alter states. Additionally, discussions with people with a DID diagnosis have illustrated that alter states can relate to people in caring professions in different ways from the central persona, suggesting relational patterns and needs vary within the person's internal working model (Parry, Lloyd & Simpson, 2016).

A recent multiple mediation analysis exploring childhood influences upon the development of dissociation (Schimmenti, 2017) and subsequent critical commentary (Garofalo & Velotti, 2017), further highlight the ongoing and complex explorations around the links between emotional neglect, dissociation, and developmental trajectories of emotional regulation and mentalising. Although it is currently unclear as to whether the interaction between difficulties in regulating emotions and mentalisation are additional triggers for dissociation, the aforementioned authors conclude that further longitudinal and clinical research is required. Additional clarity and understanding of the developmental and contemporary experiences of DID is necessary to consider what is helpful towards effective assessment, treatments and support, highlighting a need for controlled studies of dissociation (Bailey & Band, 2017). While a comprehensive and established construct of DID that can be operationalised across diagnostic frameworks, formulation processes and practice remains elusive, enough is understood of the experience to recognise the concept and explore the individuality of the lived experience further.

In light of the scarcity of comprehensive guidelines based on extensive clinical examples for non-therapeutically trained practitioners to work effectively and individually with people experiencing DID in the United Kingdom, the author's original study aimed to explore how people experiencing moderate to high levels of dissociation perceived relationships with multidisciplinary healthcare staff on hospital wards (Parry, Lloyd & Simpson, 2016). In the original study, seven participants were asked to discuss their relationships with hospital staff on physical and mental health wards. During the discussions, the five participants with a diagnosis of DID were also keen to provide insights into their personal experiences of living with alter states and how their experience of DID influenced their relationships with others and themselves. Such accounts are necessary for practitioners to understand the diversity of experiences and relational needs amongst people with alter states. The few existing qualitative and in-depth studies around experiencing dissociation suggested that positive therapeutic relationships could facilitate the reconnection and integration processes with parts of the divided self (Gill, 2010; Hirakata, 2009; McAllister et al., 2001). Moreover, in facilitating inter- and intra- personal reconnection and wider attachment changes (Mikulincer, Shaver, & Berant, 2013), safe and secure relational connections appear essential for healing and wellbeing.

Personal accounts can provide an insight into another's perceptions (Kalitzkus & Matthiessen, 2009) and thus provide the most accurate and realistic first-person perspective on this unique phenomenon. Specifically, due to the unique perceptual difficulties experienced by people with DID, it is essential to hear first person accounts of meaning making processes in relation to lived environments and the 'self' (Mattos, Pedrini, Fiks, & de Mello, 2016). Finally, McAllister et al. highlighted that greater understanding of the subjective experiences of people who experience dissociation in hospital is required in order to help professionals "respond with greater sensitivity and efficiency" (2001, pp. 32), although little qualitative research, which offers suitable ways to understand these accounts with clients and patients of services experiencing DID, has been undertaken since. The following analysis of individual accounts offers new insights into the impact of DID on relationships with the self and healthcare professionals. Further understanding of the complex and bidirectional relational factors is essential for practitioners working to support people with DID in health and social care services to understand, so as to offer suitably tailored support.

## 2. Method

### 2.1 Design

The five personal accounts presented in this paper developed from a larger empirical study that explored experiences of people identifying as having moderate or severe forms of dissociation and their encounters on in-patient wards in the National Health Service (NHS) in England (see Parry, Lloyd & Simpson, 2016). In order to preserve the perspective of the participants, the interview guide for the original study was flexible (Hefferon & Gil-Rodriguez, 2011) and participant led. This approach meant that there were passages within the interviews with the five participants with a DID diagnosis, through which they elaborated on their experiences of DID in relation to their sense of self and relationships with healthcare staff, as they discussed how they had made sense of their experiences. Participants were keen for their accounts to influence the assumptions, perspectives and understanding of DID for practitioners. Consequently, the first author liaised with the ethical governance body that oversaw the original study, to ensure that a secondary analysis on the original data would be an acceptable means through which to fully explore these accounts.

Interpretative Phenomenological Analysis (IPA) was considered to be the most relevant analytical framework for the study as the inductive and idiographic nature of IPA can explore the “unique individual experiences” of the participant (Kellett, Greenhalgh, Beail, & Ridgway, 2010, p. 144), necessary for experiences as unique as DID. That is, IPA is a particularly helpful analytical tool when exploring a person’s individual experience and perspective of a phenomenon, in this case, DID. Finally, due to the idiographic tradition of IPA (Smith et al., 2009; Osborn & Smith, 2008), the individuality and in-depth analysis within this small sample was maintained throughout the analysis, important for this exploratory study. In the light of a recent medico-philosophical consideration around the characteristics of dissociative diagnoses, Güell, et al. (2017) discuss the benefits of taking a philosophical approach towards understanding a yet debated group of experiences, exploring personal perspective through the expression of awareness and one’s memories. To this end, IPA offered both a platform for reflection and a framework for analysis that maintained individuality and depth of insight around DID.

### 2.2 Procedure

Participants self-referred to the original study through adverts placed with appropriate newsletters and sent by email to therapists registered with the European Society of Trauma

and Dissociation in the UK (ESTD-UK) and NHS, in accordance with ethical approval. The qualitative data of the five participants who reported a DID diagnosis were then further analysed to explore personal experiences of DID. All participants chose their own pseudonym.

### 2.3 Participants

The individual accounts of five women formed the data set of this study ( $M_{age} = 46.6$  years,  $SD = 3.14$ ) and facilitated in-depth explorations of idiographic experiences. Interviews lasted between 52 and 103 minutes, with each participant interviewed once, apart from Mel who requested a second interview. The length of time participants had spent on hospital wards varied between four weeks and four years, although all participants had experienced recurrent admissions in numerous locations on both physical health and mental health wards, as well as a reportedly high number of accident and emergency centre admissions due to accidents at home or self-injuries. All participants discussed childhood experiences of interpersonal complex trauma, which they related to their dissociative experiences in childhood and adulthood. At the time the study was conducted, all participants had received or were accessing psychological support that was specifically tailored around DID. The inclusion criteria for those who took part was: (1) to have been on a National Health Service (NHS) ward for at least two weeks within the last two years (Frank & Gunderson, 1990), (2) engaged in a therapeutic relationship with a ward-based health professional; and (3) score at least 30 on the Dissociative Experiences Scale-II (DES-II; Carlson & Putnam, 1993). In addition to high DES-II scores ( $M_{Score} = 72$ ,  $SD = 10.56$ ), all five participants who contributed accounts to this study had received a diagnosis of DID.

Research has suggested that people with a trauma history are likely to score higher on the DES-II than people who have not experienced trauma (Raudsepp, 2006; Shin, Jeong, & Chung, 2009; Van den Hout, Merckelbach, & Pool, 1996). However, the experience of trauma itself does not necessarily lead to higher DES-II scores (Van Ijzendoorn & Schuengel, 1996). Consequently, the study did not exclude based on the aetiology of dissociation, as past experiences were not assumed to influence how participants dissociated, only that participants had developed the ability to dissociate due to some cause.

Lastly, the homogeneity of the sample derives from the experience of dissociation and the purposive sampling of people who had experienced treatment on NHS hospital wards. Homogeneity was important within the sample because of the rationale of IPA, which suggests a participant sample should be well-defined, rather than arbitrary, so that the



research question is increasingly meaningful, even on an individual basis (Smith & Osborn, 2003).

### **2.4 Ethical Considerations**

The original study (Parry, Lloyd & Simpson, 2016) was approved by a committee who specialise in qualitative research through the NHS Integrated Research Application System and appropriate research and development (R&D) offices. Upon completion of the first study, guidance was sought as to whether a secondary analysis on the data could be performed, to further explore the personal accounts of DID specific experiences that participants discussed. The ethical review committee confirmed this approach was in accordance with the initial application. Further, approval was sought from the research committee of the ESTD-UK, which includes experts-by-experience, academics and clinicians.

All interviews were undertaken by the first author. Prior to the start of each interview, the first author explained the interview procedure and invited each participant to take a lead in terms of the information discussed. Following this, the first author confirmed whether the participant would still like to take part. All participants asked that recording continued if the person dissociated but that the first author request their central identity to return to complete the interview, rather than trying to engage an alter in the interview directly. However, none of the five participants who reported DID dissociated to an alter during our interviews.

Throughout the interviews, several safeguarding issues emerged regarding the treatment of four of the participants in hospital. All but Mel had already submitted formal complaints following the safeguarding incidents. Consequently, support was offered to Mel through her care coordinator so she could explore whether she wanted to pursue a formal complaint (advice available in BPS guidance, 2014b).

### **2.5 Analytic Approach**

IPA aims to explore the “participant’s cognitive and affective reaction” to their experiences and acknowledges there is a “chain of connection between embodied experience... and a participant’s making sense of, and emotional reaction to, that experience” (Smith, 2011, pp. 10). Therefore, IPA was an appropriate analytical method as it was most fitting for the sample population who were assumed to potentially have some difficulties in integrating emotional and cognitive experiences.

IPA is also based upon a double hermeneutic, or bi-directional interpretation, as the researcher interprets the interpreted accounts of the participant (Smith, Flowers, & Larkin, 2009). Therefore, a degree of experiential distance was recognised in terms of emotional representation and the selection of experiences recollected throughout the interviews. However, this is not considered a weakness as the participant, not the researcher, creates the initial interpretation and dictates the selection of accounts to explore their perception of experiences (Brocki & Wearden, 2006).

Lastly, an epistemological stance of critical realism was taken, which discerns the “essence of things from their appearance” (Losch, 2009, pp. 86), thus facilitating finding the nuances in the data to illustrate experiential subtleties. Epistemological and empirical discussions highlight that autobiographical accounts are based upon perception rather than fact and are therefore subjective (Bedard-Gilligan & Zoellner, 2012), which is highly relevant to this sample due to the recognised difficulties people experiencing DID can have in terms of autobiographical memory (Holmes et al., 2005; Huntjens, Wessel, Hermans, van Minnen, 2014). Although almost all autobiographical accounts in any population are subject to perception and interpretation over time, cognitive and emotional interferences for people with DID are particularly likely to influence personal accounts and potentially make them richer and more multifaceted as it may be that a range of insights are provided by the central persona.

### **3. Findings and Discussion**

Three themes emerged from the secondary analysis exploring personal experiences of DID, which are presented and discussed in relation to the existing literature base. The first theme explores the participants’ accounts relating to time discrepancies between parts of the dissociated self (alter states) and perception difficulties. Secondly, the participants’ reports regarding how the functioning of the alters influences other relationships is discussed in the context of differing relational needs within the person’s internal working model (Bowlby, 1969). Finally, the participants discuss the difficulties in conveying their unique and complex experiences to others and the impact of confusion and misunderstandings.

**3.1 Theme One: Recognising who I am and when I am in time** - “Something bad is going to happen to you if you show any emotions” (Hermione)

Participants reported a range of childhood abuses, which influenced their perceptions of environments as adults and enhanced their perception of threat and danger on the wards.

For instance, Hermione explained how childhood learning experiences influenced how she related to ward staff in adulthood: “he [abuser] trained you to take pain... if you show any sign of emotion you’re in trouble”. Therefore, despite often feeling very distressed on the wards, Hermione found it difficult to communicate this to staff for fear of inciting further “trouble”. Similarly, Mel explained how the way in which staff had responded to her four year old alter’s request for a cigarette had made her feel disbelieved and judged: “They thought I just wanted a cigarette and not dissociating. But I was and I did smoke at four.” Seemingly, participants suggested some staff members were unable to recognise that participants were not necessarily reacting to experiences and relationships in the present, but rather in their pasts.

Additionally, participants discussed the phenomenon of specific time perception difficulties as they dissociated to an alter. Van der Hart and Steele (1997) contextualise such difficulties as learned coping mechanisms, which participants seemed to suggest transcended to how they related to ward experiences and staff. For instance, Ellie explained that she would feel disorientated and detached from time when she dissociated to an alter, which could make it harder to reconnect with her support worker if the support worker “didn’t know what to do” when Ellie returned to her central persona. Mel also discussed the difficulties of “lost time”. Specifically regarding autobiographical memory, Huntjens, Wessel, Hermans, and Van Minnen (2014) found that people with DID struggle to access specific memories from their past, which can influence present day solution finding and emotional regulation. It may be that the difficulties around communicating, managing and tolerating distress in combination with autobiographical memory and time perception difficulties affected how participants perceived and responded to contemporary situations on the wards.

Particular experiences seemed especially upsetting for younger alters, such as when younger alters were overlooked or ignored. For example, Amelia described how: “My upset was about non-acceptance of who I was.” Additionally, Amelia also explained how difficult it was for her younger seven year old part who “didn’t realise I had a stroke”, as the event hadn’t happened in her lifetime. Such accounts suggest that some alters have their own chronological timeframes that are not always connected to the central persona. These accounts also highlight the impact of time perception difficulties for the participants and their alters in terms of the possible disconnect between intrapersonal connections. The participants’ awareness of and struggle with their alters who had not grown with them or shared key life events seemed to cause disruptions in time perception and also how the whole

self could relate to ward staff. Additionally, it may have been that the limited abilities of the body caused further confusion and disorganisation for younger alters without knowledge of key events. For example, Sam described how she wanted staff to recognise her whole self: “say good morning to Alter four, or Alter two! Or hi everybody!” Interpretatively, as it was often the younger alters who had experienced abuse from attachment figures, it may have been that the perception of being unrecognised by adults in roles of authority and care may have been particularly distressing and reminiscent of previous traumas and re-traumatising in the present.

Two of the participants explained how their youngest alters were not only in a different time, but functioned at a different developmental level, in line with the ages the participants thought them to be. For example, Mel discussed incontinence, “I can’t control it. And I am incontinent” and Amelia explained how her younger part would still want to play, even shortly after the stroke. These examples suggest the person’s physiology may also be significantly influenced by the aforementioned disruption of space and time in relation to the development and sense of self (Mattos, Pedrini, Fiks, & de Mello, 2016). The only emotions Mel, Ellie and Amelia described in relation to these experiences were frustration and embarrassment, although this appears a key area in need of further understanding.

Of all the participants, Amelia discussed having the most control over her alters and explained how she would compassionately respond to her younger alter once she returned to the central position: “when I would come back I would ask if we had a good time”. The ability to offer internal acceptance towards alters, explicitly demonstrated by Amelia and sometimes Ellie, appeared strongly connected to regulating the alters and meeting their needs.

Participants also discussed how the difficulties they experienced influenced their memories and the processing of information through their various parts. Mel and Sam in particular, who both had many parts and reported difficulties keeping the central space, i.e. their central persona, among them, defined particular difficulties: “he said he had a letter, social worker said yes you sent a letter but I couldn’t remember... it’s hard work, when you can’t remember. The next day someone says hello but we don’t know we said hello yesterday”. Such instances had a significant impact on the participants’ sense of safety and the response of staff to the “lost time” was especially important. For instance, Mel explained: “when I came round she told me what happened... and I was really embarrassed... sometimes you don’t want to know. When they walk away, you just go and cry. Why can’t I be normal?” Such instances illustrate the importance of reaching prior agreements through

personalised care plans with people experiencing DID in terms of supporting people through recovering from periods of lost time and memories, while ensuring the wellbeing of the central persona.

**3.2 Theme Two: Understanding the needs of the participants' internal system - "I just think they didn't know what to do" (Ellie)**

Participants recognised that they and their alters had specific interpersonal needs. In some cases, participants reported that staff noticed and tried to meet these needs. For example, Ellie reported a good relationship with the occupational therapist (OT), explaining: "I wanted to talk to her because she interested in me, she was actually interested... she at least showed some interest in care... she made me feel like a normal... like I should do I guess... like a normal person" This phenomenon of dual normality within the patient-staff relationship seemed highly important to how participants thought they were perceived and how they could connect with staff in a collaborative and equal manner. In this sense, sharing common ground and reducing feelings of difference seemed to foster hope, connection and trust. Trust has been cited as particularly important for people experiencing high levels of dissociation in that they can develop the ability to "experience a depth of trust and safety in themselves, others, and the world" (Hirakata, 2009, pp. 311) if able to feel genuine trust and safety in a relationship with another person.

However, all participants reported experiences of relational courtesies being overlooked. For example, Ellie found she "didn't get the communication with the medical staff that I would have got [on a mental health ward]... if I didn't have DID, I'd have been in and out within a week", as she suggested there was confusion around the support she would require at home. Similarly, Hermione discussed how: "there's no one available to say 'I really feel like crap, can we talk?'". Throughout all of the accounts were suggestions that participants saw talking to someone about how they felt as an alternative container for their distress, which if not managed, seemed to lead to further dissociative experiences because of the emotional regulation difficulties that the participants reported. In relation to containing distress, participants seemed to suggest that alters shared distressing truths within, rather than between them, thus containing distress in manageable compartments within alters. In this way, the participants' internal systems, with their respective alters, worked to contain aspects of emotional distress, for example "if we were Sam only we would not survive... to be safe we have to be all of us, if we switch we can't remember what we know is true."

Additionally, participants described dissociating most frequently when witnessing staff members displaying distress, misunderstanding participants' needs or when they felt trapped: "I just didn't want to be there so I just kind of went away and left it to other parts of me" (Ellie). Barlow and Chu suggest that dissociation is a means "to keep relationship-threatening information out of conscious awareness and memory." (2014, pp. 5), or as Sam explained: "if we switch we can't remember what is true". Such experiences have been described elsewhere as a disconnection between space, time and the self, which cumulatively interrupt the flow of meaning making processes and even the disjointedness of people around the person (Mattos, Pedrini, Fiks, & de Mello, 2016). Importantly, during periods when participants frequently switched between alters, relationships with staff also appeared to be occasionally confused with relationships to alters. For example, Mel explained that although being supervised on a one-to-one on the wards brought certain challenges, she felt the loss once the support workers left: "When they go you feel lost, you've lost something, a part of you is missing". Further, Amelia described a similar disruption experience as "My head felt like a clock face, no one was in the right place." The disorganisation and confusion that participants reported in relation to their experiences of their alters was mirrored in their relationships with others too (see Parry, Lloyd & Simpson, 2016).

Specifically in terms of how DID influences relationships, a recent comparative study suggested people with DID experience elevated relationship anxiety, depression and fear about relationships compared to participants with complex PTSD and a non-clinical group, with shame being an additional compounding factor towards relationship anxiety and fear (Dorahy, et al., 2017). Support for these findings appears in the current accounts, particularly around dissociating to younger alters; for example, Ellie described her thoughts after dissociating to a younger alter: "what have I done, have I done anything wrong, have I embarrassed myself... feeling uncomfortable and wanting to leave hospital". In addition, there were anxieties described associated with staff appearing unequipped to support participants, which appeared to increase anxiety, leading to further dissociative coping strategies. Perhaps due to such relational difficulties and exacerbated dissociative experiences, participants developed a range of self-management strategies.

Further frustrations were reported by participants as they perceived the ward staff did not understand the functionality of dissociative, distracting and soothing coping strategies. For instance, Mel and Hermione both discussed experiences of presenting to Accident and Emergency (A&E) services for help following self-injuries and explained how they had felt

shamed and judged by the staff who attended to them, which exacerbated their dissociative coping strategies. As discussed in other qualitative empirical research exploring experiences of accessing support following self-injury (Thomas & Haslam, 2017), personal care plans and awareness of barriers to care is crucial, as is awareness of the impact of additional relational anxiety triggered by shaming (Dorahy, et al., 2017) and stigmatising a person's current methods of managing distress, such as self-injury. Indeed, Mel explained how one experience of attending hospital following a self-injury during a dissociative episode meant she self-managed subsequent injuries, which sometimes became infected: "Once in A&E I was being stitched up by a doctor and he was laughing at me."

Participants had a range of coping strategies during and after dissociative periods, which could be as varied as the different alters: "Some of us like music... music seems to makes us back to reality... It calms us down... just numb to it all" (Sam). Similarly, although Amelia had felt largely unsupported by the medical team in relation to her DID after her stroke, she implemented self-care strategies to good effect: "Within three days I could sort out what was wrong. I did some Tai Chi and meditation and my head almost shifted back". Throughout the participant accounts, compassionate acceptance of the younger alters, supporting the needs of everyone in the system and implementing a range of self-management strategies directed towards the needs of each alter with recognised vulnerabilities, was particularly effective. Such information appears invaluable to include in person-centred care plans.

**3.3 Theme Three: Trying to help others understand what the self doesn't always fully understand** - "[therapist] did a great job with the nurses, more understanding after" (Mel)

Although all of the participants understood much of how their dissociative experiences influenced them in various ways, it appeared difficult to articulate that understanding to others at times of distress. During the interviews, participants were able to describe their experiences as though narrating events they had witnessed. For example, Sam described the experience of witnessing changing to an alter: "We can see ourselves leaving our body but can't help it...when you are changing but can't stop it". However, it appeared to be only the central persona who was able to provide this overview. All participants offered examples of difficulties in conveying their complex experiences to others when experiencing distress and dissociative switching, although it appeared to be at these times when ward staff would look to participants for explanations as to what was happening.

Articulation of dissociative difficulties was most challenging during times of increased distress, which often led to participants feeling misunderstood and added further stress to times of crisis. Such reports also highlight how much of the responsibility surrounding identifying and facilitating understanding of DID lay with the participants, even on acute mental health wards. On a few pivotal occasions, Mel, Ellie and Sam all reported positive experiences of clinical psychologists or psychiatrists offering ad hoc training or education around dissociation to ward staff, which was reported as validating and useful. However, Amelia wrote her own care guidelines and Hermione reported a series of distressing experiences in hospitals during which time she felt as though she had been overlooked as a result of staff not knowing how to support her during certain experiences, such as when she reported being “frozen” when she would be unable to move or communicate with others. Additionally, Hermione explained how anxious she sometimes felt talking about her experiences, anticipating the anxiety of professionals when she would try to explain her dissociation, both in terms of the experiences themselves and what she feared would happen if she dissociated in their company. For example, “I can’t ever talk... to talk about anything if you feel distressed you might dissociate”.

There were a number of other relational barriers to accessing help and support for participants also, connected to a perceived lack of awareness and training in dissociative conditions amongst care staff. For instance, Amelia discharged herself from hospital following her stroke early due to her concerns that hospital care would delay her recovery: “I would’ve probably stayed in hospital longer... but I recovered more quickly at home”. Such reports suggest a lack of trust and faith in some of the hospital staff with whom participants of this study liaised, perhaps due to both past experiences of hospital care and distressing schemas, or thinking frameworks, around attachment figures as discussed in section 3.1. Such barriers to communication and understanding of DID, perhaps often due to lack of training for professionals around dissociation and DID, resulted in less collaboration towards patient-led care plans in many instances.

The therapeutic utility of tailored care plans and guidance around multidisciplinary complex care is well supported in the clinical literature (e.g. Farrelly, et al., 2014; Leonard, Graham, & Bonacum, 2004). However, the reported lack of collaboration and forward planning described by the participants is concerning, as is the onus for providing guidance for staff in times of crisis seemingly lying with the participant. There are clear indications within the participants’ accounts that articulation of dissociative experiences and needs is



particularly difficult during periods of exacerbated distress, which further indicate the need for preventive planning and informed psychological support (Lloyd, 2015). Similar results around barriers to service user led care plans have been found elsewhere in the psychosis literature, with clinician apathy, misunderstanding as to the level of engagement required to recognise service user choices, and poor collaboration being key to undermining the process (Farrelly, et al., 2016). The participants of the current study reported struggling to find a balance in power with many ward staff that would have helped facilitate collaborative care planning. There also seemed to be barriers to communication around dissociative experiences, with participants often feeling unable to discuss their needs when particularly distressed and uninvited to voice their requirements when not in crisis.

Sam also found a lack of awareness of dissociation contributed to the loneliness she felt: “They’re supposed to be helping you, expectations they can fix us...” Although these aspects of the data seemed connected to being heard and listened to, there was an additional frustration from participants around perceiving staff who had been trained in helping professions as unable to understand dissociative conditions. For example, Hermione explained how: “It’s not like you have PTSD with a touch of dissociation... how can I exist if they don’t think I [DID] exist...” Sam and Hermione seemed to suggest that if DID was not recognised, they were not recognised, which influenced upon their already fragile sense of a whole self.

#### **4. Concluding Discussion**

In summary, the findings of these unique personal accounts of DID indicate alters have specific life times, ore developmental characteristics, which means younger alters are often not aware of key life events or strengths of the adult parts. Alters also appeared to contain information within, rather than between alters, through amnesic barriers perhaps in order to manage the amount of trauma the whole self needed to manage alone. Although this containment within alters seemed to help shield other parts of the self from particularly distressing information, this process may also serve to keep memories alive and seemingly current. Therefore, perceptions of time could be disordered and feelings of threat could be enhanced in current situations and relationships as dissociative coping strategies could be triggered through perception rather than current threat. Accordingly, a number of preliminary recommendations in the form of guideposts specific to the needs of people who experience DID with younger alters in healthcare settings has emerged from the findings.

## Insights into Dissociative Identity Disorder

1. Younger parts may require additional acknowledgment, nurture and support.
2. Avoiding a singular perspective on the self as a construct may be helpful, for example, enquiring “how is everyone?” may be preferable to “how are you?”
3. Younger parts may have particular difficulties expressing themselves verbally. Therefore, alternative methods of communication should be agreed with the main persona (e.g. toys, music or drawing).
4. Different alters may require an introduction to staff known by the main persona, and vice versa.
5. Compassionate acceptance and support for people with younger parts was identified as essential for the wellbeing of the whole person.

Most of the participants reported benefitting from psychological or psychiatric support at times, although experienced many relational challenges and struggled to articulate important information about their unique conditions during times of crisis, which was often when they were invited to share information with healthcare staff. Planned person-centred care plans that benefit from the expert personal insight of people with this unique and complex condition must be sought prior to periods of crisis, which requires meaningful collaboration through trusting relationships and the removal of barriers to collaboration. The following guideposts arose from the data in relation to fostering a platform for collaboration and opening channels of communication.

6. Demonstrate authentic interest in the person’s wellbeing through asking questions and becoming educated around their individual condition. All participants highlighted what a difference staff training around complex trauma and dissociation would have made for their treatment, wellbeing and recovery. “Don’t presume, that’s the important thing. It doesn’t take long to ask the question.” (Mel)
7. Common ground was seen as being very important in order to develop relationships.
8. Participants often had difficulty recognising, remembering and locating their named nurse. Therefore, people with DID should be provided with an information card about their key staff including a photograph, name and perhaps some appropriately brief information about hobbies or interests.

Mounting empirical evidence suggests that the ISSTD recommended treatments for people experiencing DID in therapy are beneficial (Brand, Loewenstein, & Spiegel, 2014; Lynn, Lilienfeld, Merckelbach, Giesbrecht, & Van der Kloet, 2012). Therefore, initial guideposts such as those recommended in this study require further research in collaboration with existing networks and support groups so that hospital and community based treatment guidelines for multidisciplinary staff can be refined with a view to developing a cohesive and integrated support pathway for people with DID. To build on the depth of experiences explored in this report, further exploration to consider the theoretical generalisability of the findings is essential to develop a broader understanding of how to best support people with DID.

In order to expand on the findings of this small-scale study with female participants in England, similar conversations need to be had across a range of other care settings, cultures and demographic groups. Additionally, some of the particularly distressing experiences shared by the participants may have encouraged them to participate in this study, which is likely to have influenced the findings. However, the variety of positive and negative experiences reported in the accounts and the variety of wards the participants encountered may accommodate some of the personal motivations for participating in the research. Finally, there is a need for future research to explore some of the methodological issues surrounding research with alters. For example, temporal distancing from experiences, the impact of reflexive accounts through the narration of a central persona and influence of such overviews in terms of layered interpretations within an interpretative phenomenological analysis are all likely to impact findings and conclusions. Nevertheless, despite the methodological complexities associated with such research, this study has developed novel insights into the relational challenges of people with a DID diagnosis and trauma histories, which have led to the development of several important guideposts to improve care services for people with DID.

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