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ScienceDirect

Comprehensive Psychiatry 76 (2017) 18–25

COMPREHENSIVE PSYCHIATRY

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A decline in self-defining memories following a diagnosis of schizophrenia

Tine Holm[a,b,c,*], David B. Pillemer[d], Vibeke Bliksted[c,e], Dorthe Kirkegaard Thomsen[a,b]

[a]Department of Psychology, Aarhus University, Denmark
[b]Center on Autobiographical Memory Research, (CON AMORE), Aarhus University, Denmark
[c]Aarhus University Hospital Risskov, Psychosis Research Unit, Denmark
[d]University of New Hampshire, Department of Psychology, USA
[e]Department of Clinical Medicine, Aarhus University, Denmark

Abstract

Purpose: Receiving a diagnosis of schizophrenia can be a profound life transition that often has a negative influence on the patient's sense of self. The present study is the first to examine how self-defining memories are temporally distributed around age at diagnosis of schizophrenia.
Method: 25 patients and 25 matched control participants identified 3 self-defining memories from their lives. In addition, participants were assessed with standardized interviews and questionnaires on negative and positive symptoms as well as tests of cognitive function.
Results: Patients' self-defining memories increased in the years leading up to diagnosis and declined abruptly in the years immediately following diagnosis. The pre-diagnosis increase in self-defining memories was not attributable primarily to a rise in disease-related recollections.
Conclusion: The sharp post-diagnosis memory decline suggests that patients find it difficult to establish new or evolve existing definitions of self. Implications for models of schizophrenia and for clinical practice are discussed.

1. Introduction

Receiving a diagnosis of schizophrenia may be a life altering experience that can have detrimental effects on one's sense of self [1]. It can be associated with a loss of former self, including the goals and dreams that one once aspired to obtain [2], and many patients must endeavor to redefine who they are. Following diagnosis, some individuals identify with their mental illness to such an extent that this role becomes a dominating part of their self-understanding [3]. Needless to say, this can have negative consequences for well-being, such as low self-esteem, especially if it is associated with self-stigma, a process whereby negative stereotypes about mental illness are internalized [4]. Targeting the subjective consequences of illness therapeutically may be as important as treating clinical symptoms: "It is not enough just to eliminate a patient's psychosis, because many patients are as impaired by their mentally ill definition of self as they are by their disorder" (Lally, 1989, p. 264) [5]. Indeed, there is an increased awareness that rebuilding a sense of self constitutes a unique domain of recovery in schizophrenia [6].

While it has long been recognized that schizophrenia can have negative and long lasting impacts on sense of self, research in this area is still limited [7] and more work needs to be done that examines the mechanisms involved in this process. In this study, we examine how patients' self-defining memories are distributed around age at diagnosis of schizophrenia.

1.1. Schizophrenia, self, and memory

Schizophrenia is associated with positive symptoms (e.g., hallucinations), negative symptoms (e.g., social isolation), and cognitive impairments (e.g., executive dysfunctions) [8–10]. In addition, it is recognized as a disorder that can disrupt how people define themselves. In a review of reports concerning recovery in schizophrenia, Andreasen [1] noted that 42 out of 46 articles mentioned loss of former self as a

* Corresponding author at: Aarhus University Hospital Risskov, Psychosis Research Unit, Skovagervej 2, DK 8240 Risskov. Tel.: + 45 21337406.
E-mail address: Tinehol9@rm.dk (T. Holm).

http://dx.doi.org/10.1016/j.comppsych.2017.03.014
0010-440X/

central aspect of the illness. This is consistent with first person accounts by individuals with schizophrenia: "Our past deserted us and we could not return to who we had been. Our futures appeared to us to be barren, lifeless places in which no dream could be planted and grow into a reality" (Deegan, 1988, p. 13) [11]. It follows that rebuilding a sense of self following the illness is a central aspect of recovery [12]. The self is supported by memories of past experiences and individuals reflect on their past in order to understand who they are and how they have developed across their lives [13]. As such, examining how patients recall important memories can increase our knowledge of the relation between schizophrenia and sense of self.

Although individuals remember a multitude of experiences from their pasts, some stand out as more important to self-definition than others. Self-defining memories are vivid, emotional, well-rehearsed, and they revolve around the most significant life goals or unresolved conflicts [14]. The few previous studies that have examined self-defining memories in patients with schizophrenia found that patients' memories show a different temporal distribution than the memories of healthy control participants [15,16]. When normally functioning adults (age 40 and older) are asked to identify important memories from their lives, a disproportionately large number of recollections concern experiences that happened during emerging adulthood [17]. Many of the experiences that people recall from this period of life are normative and positive, such as starting the first job or getting married [18]. This phenomenon has been referred to as the *reminiscence bump* and it is a robust finding within memory research (see Koppel & Berntsen, 2015 for a review) [19]. Previous studies show that self-defining memories of patients with schizophrenia show a different temporal distribution, peaking in mid to late adolescence (15–19 years) as compared to memories of healthy control participants that peak around the ages of 20–24 years [15,16]. However, the mechanisms underlying the divergent distribution of important memories in schizophrenia are not well understood.

The purpose of the present study was to use a novel approach in order to examine the relation between diagnosis and the distribution of self-defining memories in schizophrenia: examining the degree to which memories cluster around patients' ages at the time of diagnosis. Several studies show enhanced recall of experiences that occur around the time of important life transitions, including residential relocation [20], immigration [21], starting university [22], and war or natural disaster [23]. Transitions are defined as periods where many aspects of life change simultaneously [24] and can also be psychological in nature and related to changes in self-definition. For instance, people often recall experiences that occur around the time when new self-images (e.g., the self as a parent), are formed [25]. Thus, transitions are associated with highly accessible memories.

It has long been recognized that receiving a diagnosis of schizophrenia can be a major life transition, one that is associated with significant changes in life circumstances and self-definition [5]. Yet the current study is the first to examine how patients' self-defining memories are distributed around their age at diagnosis. Because previous research has demonstrated that people have enhanced memory for events taking place around life transitions, we expected to find a marked peak in self-defining memories surrounding the patients' age at diagnosis. If patients' memories cluster around their age at diagnosis, this could be an explanation for the earlier reminiscence bump in schizophrenia.

2. Method

This study was part of a project examining life stories and autobiographical memory in patients with schizophrenia in comparison to a healthy control group. During an interview, participants were asked to freely narrate their life story, identify life story chapters and three self-defining memories from their lives. This article will focus on the last part of the interview (see Holm, Thomsen, & Bliksted, 2016 for a full description of the methodology) [26].

2.1. Participants

Twenty-five patients (11 women) with an ICD-10 [27] confirmed diagnosis of schizophrenia participated in the study. The mean age at diagnosis was 24.80 years (SD = 5.51). Duration of illness, defined here as the time interval between age at diagnosis and age at testing, was 11.80 years (SD = 7.63). All but two patients were receiving neuroleptic treatment (atypical = 18; typical =1; both typical and atypical =4). Mean level of positive and negative symptoms as evaluated by the Scale for the Assessment of Positive/ Negative Symptoms (SAPS/SANS) [8,9] was 6.92 (SD = 4.13) and 10.56 (SD = 3.42), respectively. Furthermore, mean level of anxiety and depression as evaluated by the Common Mental Disorder Questionnaire [28] was 4.60 (SD = 2.84) and 6.36 (SD = 5.33), respectively [26].

Twenty-five control participants (11 women) with no history of mental disorder or familial relation to people suffering from schizophrenia participated in the study. Patients and controls were matched for age (M = 36.60 years, SD = 9.69 vs. M = 37.52 years, SD = 10.67) and years of education (M = 15.77 years, SD = 3.01 vs. M = 16.16 years, SD = 1.92). Furthermore, while controls participants performed slightly better than patients on neurocognitive tests, as estimated by the Brief Assessment of Cognition in Schizophrenia [29], in general the differences failed to reach significance [26]. Participants were excluded if they had a history of traumatic brain injury, neurological disorder, drug- or alcohol dependency or if they did not speak Danish fluently.

2.2. Procedure and measures

The first author conducted all the interviews. The procedure was identical for patients and controls.

Participants were screened for symptoms of depression and anxiety using the Common Mental Disorder Questionnaire (CMDQ) [28]. Anxiety was evaluated with four questions (e.g., having panic attacks), while depression was evaluated with six questions (e.g., feeling worthless). Each question was rated on a 5 point scale ranging from 'not at all' to 'extremely'. Furthermore, participants were rated with the Scales for the Assessment of Negative/Positive Symptoms (SANS/SAPS) [8,9]. The SANS consists of 25 items divided into five subscales (e.g. asociality). Only four subscales of the SANS were included in this study, because attentional difficulties may not be conceptually related to the negative symptoms construct [30]. The SAPS consists of 34 items divided into four subscales (e.g. hallucinations). Each SANS and SAPS subscale consists of a number of items assessing specific symptoms. The severity of each symptom is rated on a six point scale (0–5), where higher scores reflect more severe psychopathology. A global score (range 0–5) of each subscale was estimated leading to a total score of SAPS and SANS (range 0–20). Then neurocognitive function was assessed using the Danish version of the Brief Assessment of Cognition in Schizophrenia (BACS) [29]. The battery consists of six tests measuring verbal memory, working memory, motor speed, verbal fluency, speed of information processing, and reasoning and problem solving.

Finally, participants were asked to identify three specific self-defining memories using the procedure described by Singer & Moffitt [31], translated into Danish by the first author (and back-translated by the last author). A self-defining memory was described as: 1) *At least one year old*; 2) *A memory from your life that you remember very clearly and that still feels important to you even as you think about it*; 3) *A memory that helps you to understand who you are as an individual and might be the memory you would tell someone else if you wanted that person to understand you in a more profound way*; 4) *It may be a memory that is positive or negative, or both, in how it makes you feel. The only important aspect is that it leads to strong feelings*; 5) *It is a memory that you have thought about many times. It should be familiar to you like a picture you have studied or a song you have learned by heart.* Participants narrated the memories out loud and included information about their age at the time of the event.

Participants were asked to briefly describe their memories (e.g., "the day I met my boyfriend") before they narrated them. To examine whether the temporal distribution was influenced by illness related memories, patients' brief descriptions were coded as illness related or not. Illness related descriptions referred to treatment, hospitalization, or diagnosis. All descriptions were coded by the first author and by an independent rater and there were no disagreements between raters; kappa =1.00.

3. Results

The mean number of self-defining memories produced by patients (M = 2.36, SD = 1.08) did not differ from control participants (M = 2.60, SD = 0.82), $t(48) = -0.89$, p = .38, d = 0.25. However, as illustrated in Fig. 1, patients' memories showed a different temporal distribution, peaking at an earlier age (15–24 years) than controls (25–34 years). In order to examine differences between groups in the number of memories produced within the different age spans, we conducted a series of t-tests. Although t-tests are not optimal because the memories do not represent independent data points, we ran the analyses in order to make our results comparable to previous studies that have used a similar procedure [15,16]. Patients produced significantly more memories from the 15–19 year age bin (M = .60, SD = .76) than control participants (M = .24, SD = .44) $t(48) = 2.05$, $p < .05$, d = .58. Conversely, the mean number of memories produced from the 25–29 year age bin was significantly higher for controls (M = .56, SD = .77) than for patients (M = .16, SD = .47), $t(48)$ = 2.22, p = .03, d = .63. The groups were matched for age;

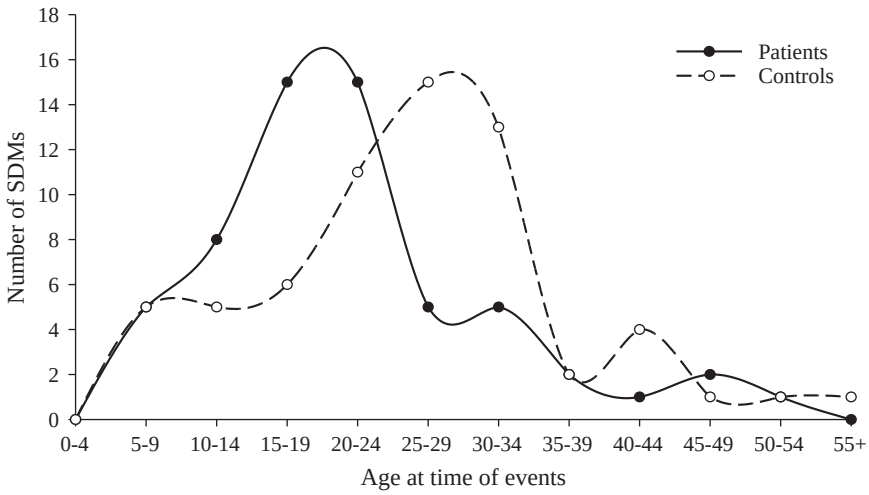

Fig. 1. Temporal distribution of recalled self-defining memories (SDMs) in patients and controls.

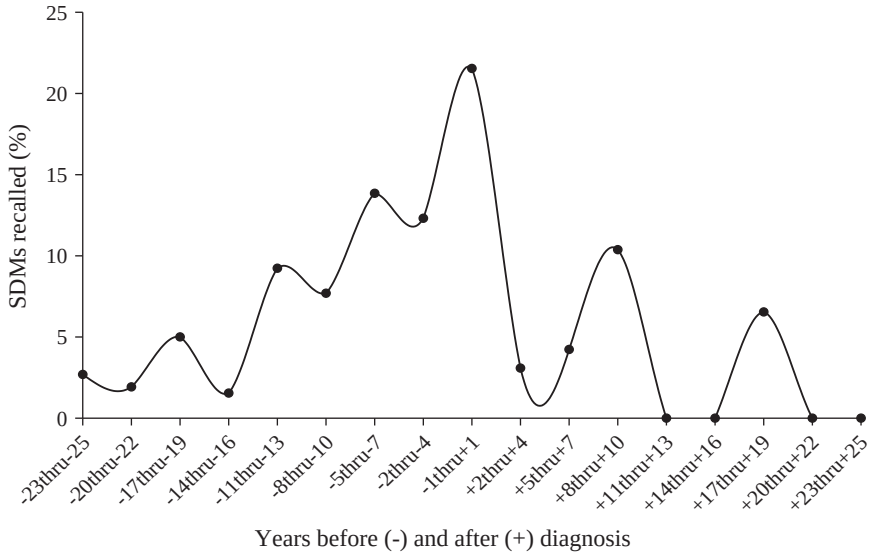

Fig. 2. Distribution of self-defining memories (SDMs) in patients with year of diagnosis set to zero, memories from before diagnosis to the left (−), and memories from after diagnosis to the right (+).

hence the number of participants between 15 and 35 years at the time of testing, did not differ between the groups and thus cannot explain the group differences. No significant difference was observed for any of the other age bins *ts*(48) range = .00 to 1.74, *ps* > .08. The results are consistent with the previous studies that examined the distribution of self-defining memories in schizophrenia [15,16].

We then examined how patients' memories were distributed around their age at diagnosis. The age at diagnosis for each patient was set to zero and the distribution of memories was centered around this point (a method that has previously been employed by Enz et al., 2016; Schrauf & Rubin, 2001, and Svob & Brown, 2012) [20,21,24]. For example, if a patient who was diagnosed at age 20 recalled an event from age 15 and another event from age 25, the ages of the memories would be −5 and +5 as these represent the temporal distance of the memories from the year of diagnosis. We then grouped the centered memories into 17 bins of 3 years, with 8 bins before, 8 bins after year of diagnosis, and a center bin corresponding to memories for events that occurred one year before, one year after, or in the same year as patients were diagnosed. One concern when using this procedure, in relation to the present sample, is that patients had different ages at testing and when they were diagnosed and consequently the number of patients represented in each bin is not equal. For example, while most patients had lived with their diagnosis for several years when they were tested, fewer had lived with it for 20 years. This is critical, because we might see a decrease in memories in the years following diagnosis simply because fewer patients are able to identify memories from those years. We corrected for this by calculating the proportion of memories within each bin (number of memories in each bin divided by the number of participants who could provide memories in that bin). Bins with less than 3 patients were excluded from the analysis. As Fig. 2 illustrates, a substantial proportion of self-defining memories identified by patients were located in the years before (63%) rather than after the year of diagnosis (27%). When inspecting the proportion of memories from the years immediately surrounding diagnosis in isolation, a dramatic drop in memory incidence is evident: 22% of all memories produced were from the 4 year interval preceding the year of diagnosis (−1 thru −4), 9% of memories were from the year of diagnosis (0) and only 6% of memories were from the 4 year interval following diagnosis (+1 thru +4). To examine whether the increase in memories surrounding age at diagnosis was simply a result of more illness related memories being identified from that period, we excluded illness related memories ($N = 14$). The pattern of results remained largely the same with 69% of memories identified from before diagnosis, 27% from after diagnosis, and 4% from the year of diagnosis; 18% of memories were from the 4 year interval immediately preceding the year of diagnosis (−1 thru −4) and 6% of memories were from the 4 year interval following diagnosis (+1 thru +4).

Finally, we examined whether duration of illness and symptoms were associated with patients' ability to retrieve self-defining memories in general and specifically following diagnosis (see Table 1). While the duration of illness was not related to the number of memories produced overall, patients with a longer duration of illness identified more memories from the years following their diagnosis. Although anxiety, depression, and positive symptoms were not significantly related to the number of memories produced, negative symptoms were. Patients who displayed more negative symptoms produced fewer self-defining memories overall and especially following diagnosis.

Table 1
Correlations between number of self-defining memories (SDMs) produced (in total and following diagnosis), duration of illness, and symptoms.

	Number of SDMs	Number of SDMs following diagnosis
Duration of illness	−.22	.44*
Anxiety	−.26	−.26
Depression	−.15	−.34
Positive symptoms	−.28	−.23
Negative symptoms	−.45*	−.69**

*$p < .05$, **$p < .01$.

4. Discussion

The present study examined how self-defining memories were distributed around age at diagnosis of schizophrenia. Patients' memories peaked at an earlier age than control participants. Furthermore, memory incidence increased markedly during the years immediately preceding the year of diagnosis and declined precipitously in the years that followed. This could suggest that receiving a diagnosis of schizophrenia impairs the formation of self-defining memories, at least temporarily. These findings support previous first-person accounts describing an impoverished sense of self following a diagnosis of schizophrenia [11].

The current finding that patients' memories showed an earlier reminiscence bump is in agreement with previous studies that show a reduction in memories from early adulthood in patients with schizophrenia, a period where many receive their diagnosis [15,16,32]. Previous interpretations of this memory reduction have emphasized neurocognitive impairments and negative symptoms. For instance, negative symptoms, such as isolation and social withdrawal, could limit patients' exposure to many of the memorable experiences that occur in emergent adulthood, including establishing a career, getting married, and starting a family [15,16]. Consequently, these experiences do not become part of patients' self-definition. The current study is consistent with this idea, since a higher level of negative symptoms was associated with fewer self-defining memories.

Alternatively, memories of experiences that occur after illness onset may not be well-preserved, because the neurocognitive dysfunctions associated with the illness interfere with memory encoding and consolidation [32]. However, this interpretation is not consistent with our finding of a peak in memories from the time immediately preceding diagnosis, a period where symptoms are already present. People who suffer from schizophrenia often display neurocognitive dysfunctions several years before they are diagnosed [10] and neurocognitive dysfunctions appear to remain stable regardless of clinical state [33,34]. Thus, if neurocognitive dysfunction is responsible for the paucity of memories, we would expect a decrease in memories from the years preceding diagnosis; in contrast, in the present study a prominent increase in memories is apparent (see Fig. 2). Furthermore, memories showed a different distribution in the two groups in spite of the fact that patients' performance on neurocognitive tests was comparable to that of controls (see Fig. 1). This suggests that the reduction of self-defining memories for emergent adulthood observed in schizophrenia cannot be attributed primarily to a decline in neurocognitive function.

Another reason that memories show an earlier bump in schizophrenia may be that they are organized around age at diagnosis, which may represent a major transition in patients' lives. Receiving a diagnosis is accompanied by changes in self-definition and life circumstances (e.g., education, housing, treatment) which could mark it as a transition. In line with previous studies examining the effect of transitions on memory [20,23], we found a marked increase in memories in the years immediately preceding diagnosis. One explanation could be that illness related experiences are relevant to self-definition in schizophrenia and therefore remain highly accessible in memory. However, excluding illness-related memories (treatment, hospitalization, or diagnosis) did not fundamentally change the pattern of results; memory incidence continued to rise through the formative years of late adolescence and early adulthood up to the point of diagnosis. This indicates that diagnosis organizes self-defining memories broadly speaking and not just memories that are related to the definition of self as ill.

There is a wide-ranging agreement that many individuals suffering from schizophrenia experience themselves as diminished [1,35]. However, there is some disagreement as to whether this diminishment predates the illness. Some phenomenological models suggest that compromised self-experiences mark the early phase of schizophrenia. For example, Parnas (2011, p.1124) describes how "self-disorders are persisting and often pervasive (trait) phenomena, whose onset usually dates to early adolescence or even childhood" [36]. In contrast, dialogical models suggest that difficulties in relation to sense of self can appear suddenly and that individuals "may have rich internal experiences only to have them fray with the onset of illness, resulting in a sense of self as diminished" (Lysaker & Lysaker, 2010, p. 337) [35]. The fact that in the present study patients' self-defining memories continue to rise up until the point of diagnosis suggests that memories are evolving as is sense of self prior to the onset of illness. This would appear to be most consistent with the idea that the diminished experience of self occurs in close association with diagnosis. However, prospective studies of at-risk individuals are needed to clarify this issue further.

Unlike previous studies examining the effects of transitions on memory, we found a dramatic drop in memory incidence in the years following the profound transitional event of diagnosis. Being diagnosed with schizophrenia can disrupt the period of identity formation and existing self-images may no longer be viewed as relevant or even possible due to the illness. In first person accounts this has been described as a detrimental loss of former self (e.g. Deegan, 1988) [11] and it is reflected in the results of the present study, where the four year period following

diagnosis is characterized by a notable scarcity of self-defining memories. It is possible that experiences that take place following diagnosis cannot be reconciled with patients' self-understanding, interrupting emerging ideas about the goals and dreams that they once aspired to attain. As a result, these experiences may not become part of their self-definition. It is well established that people are deeply motivated to maintain or increase a positive definition of self and this motive shapes how the past is remembered [37]. Not identifying with experiences that take place following diagnosis may protect patients' sense of self from contamination by the negative consequences of their diagnosis. This could be an adaptive strategy; when negative experiences are made central to identity, this can increase emotional distress [38].

Although some patients may avoid identifying with their diagnosis, others may incorporate it as a persistent and defining aspect of their identity [3]. When associated with self-stigma, it can lead to despair and hopelessness and it can complicate the formation of an adaptive post-diagnosis identity [6]. For example, some patients may embrace negative beliefs that are false but widely held — that they are incompetent, dangerous, or that they will never recover from their illness [39]. As a result, they may start living a life where they become invisible to themselves as protagonists and they may view themselves as unworthy or unable to influence the course of their own lives [40]. The number of self-defining memories may be reduced following diagnosis because individuals, based on self-stigmatization, come to expect a restricted life with little exposure to positive normative experiences (e.g., marriage and parenthood) that under normal circumstances would have become new or evolving components of their self-definition. Indeed, an important aspect of recovery involves the person's active efforts to regain and strengthen an effective sense of self and "identifying those other things the person can still do in spite of the illness" (Roe & Davidson, 2005, p.93) [40].

Finally, the reduced number of self-defining memories following diagnosis may be associated with a diminished capacity for metacognition. For example, several studies have demonstrated that individuals with schizophrenia struggle to form integrated and complex ideas about themselves, others, and the world [41–43] and those difficulties cannot simply be reduced to neurocognitive impairment [44]. It is possible that the synthetic capacities required to evaluate the meaning of experiences and their importance to self-definition are impaired in patients as a result of the illness, which could be another reason why fewer self-defining memories are formed from the period following diagnosis. In the current study, a lower incidence of self-defining memories (in particular after diagnosis), was associated with a higher degree of negative symptoms. This finding is consistent with previous studies showing how difficulties in metacognitive capacities are associated with negative symptoms both concurrently and prospectively [45–48]. Thus, the combined effect of negative symptoms and metacognitive difficulties could impair the formation of self-defining memories following diagnosis.

If a diagnosis is perceived as a major life transition, age at diagnosis and its association with memory distributions may not be unique to schizophrenia. For example, a recent study demonstrated a reduction in memories following spinal cord injury [49], which restricts the range and nature of activities individuals can engage in. This suggests that any illness or disability that fundamentally changes life circumstances and/or identity can affect memory distributions. It is worth considering whether self-disorders and associated memory abnormalities observed in schizophrenia are a symptom of the illness itself or a consequence of profound material and psychological life changes that accompany living with a disabling illness.

4.1. Clinical implications

Duration of illness was positively correlated with the number of self-defining memories identified after diagnosis, which suggests that patients may eventually start to form self-defining memories as they form new self-images or rediscover and develop aspects of themselves unaffected by their illness. However, a small increase in the incidence of self-defining memories was not observed until 5–7 years following diagnosis (Fig. 2) and it could be clinically important to try to reduce this time lag. Rebuilding a sense of self constitutes a unique domain of recovery in schizophrenia [6] and interventions that specifically target how patients define themselves seem especially promising for this purpose. One example is the group-based treatment Narrative Enhancement and Cognitive Therapy (NECT) [7], which aims to correct dysfunctional self-beliefs and encourages a greater sense of personal agency. This intervention has been shown to increase self-esteem and quality of life while decreasing self-stigma [50] and it demonstrates the potential of psychotherapy to facilitate recovery in schizophrenia.

4.2. Limitations and conclusion

One limitation of the study was the small sample size and the fact that participants generated only a small number of memories. Secondly, while it seems plausible that diagnosis can lead to changes in self-definition, the study was based on a correlational design preventing inferences about causal directions. Finally, patients in the present study were in a stable phase of their illness and they were cognitively well-functioning, so that the results may not generalize to patients who are actively psychotic or display serious neurocognitive dysfunctions.

In conclusion, although the findings of this study need to be replicated to test their robustness, they suggest that diagnosis is related to the age of occurrence of self-defining memories. Patients' memories frequently represented experiences occurring before rather than after diagnosis, which could help to explain why self-defining memories show an earlier reminiscence bump in schizophrenia. Examining the ways in which diagnosis is associated with the formation and

persistence of self-defining memories may not only enrich our understanding of the impact of schizophrenia on sense of self, but also enhance our ability to mitigate its negative life impacts.

Acknowledgment

We want to thank the study participants and the therapists working at the department of psychosis (outpatient unit) in the Psychiatric Hospital in Risskov. We also want to thank researchers at the Center on Autobiographical Memory Research (Con Amore) for their feedback. The first and last authors are affiliated with Con Amore, which is funded by the Danish National Research Foundation (DNRF) Grant DNRF89.

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