



## ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH

### Developing person-centred care through the use of autobiography

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#### Abstract

*Background:* Postnatal psychosis is a serious psychiatric emergency that can have tragic consequences for the mother and child if the symptoms are not recognised early. An autobiographical account of this condition gives clinicians and researchers a unique opportunity to explore how a patient may view their episode of postnatal psychosis, and how when this account is interpreted through a biomedical lens, new person-centred treatment possibilities can be developed.

*Aim:* This paper aims to demonstrate how to understand a woman's lived experience of postnatal psychosis by examining an autobiographical account of the condition, found in *The Book of Margery Kempe*.

*Research design:* A qualitative research design based on a textual analysis approach was used.

*Methods:* The text was read against the domains of the common-sense model of illness (identity, cause, consequence, control-treatment, control-personal, coherence and emotional representation). Specific extracts were categorised into each domain and read closely to determine how a patient's account of their illness can be interpreted usefully for healthcare plans.

*Results:* The autobiographical account of postnatal psychosis gives fresh insights into how patients reconstruct the condition from memory and what meaning they may attribute to the cause, progression, treatment and outcome of the illness.

*Conclusions and implications for practice:*

- Autobiographical accounts of a patient's lived experience of illness can be powerful educational tools that healthcare professionals can use to develop a person-centred approach to treatment
- Autobiography demonstrates how not listening to a patient can have a devastating effect on the treatment a patient receives
- If researchers and clinicians come to understand how the patient makes meaning of their illness, treatment and care plans can take a more individualised and person-centred approach that could promote positive health outcomes and greater patient satisfaction

**Keywords:** Person-centred care, autobiography, reflection, textual analysis, patient's voice, puerperal psychosis

#### Introduction

The concept of person-centred care asks the healthcare professional to work in partnership with the patient to develop care and treatment plans based on the patient's needs and wants (Berwick, 2009). This approach challenges healthcare professionals to consult the patient because they can no longer assume they know what care the patient requires (McCabe, 2004). It entails the development of communication strategies in healthcare that enable the professional to perceive the patient as a person,

rather than taking a biomedical approach that sees the patient as a cluster of diseases defined by presenting signs and symptoms (Pelzang, 2010). Such strategies have been defined as 'communication that invites and encourages the patient to participate and negotiate in decision-making regarding their own care' (Langewitz et al., 1998 p 269). However, implicit in this understanding of person-centred care is the notion that the healthcare professional must understand how the patient actually makes meaning, or perceives their experience of illness (Epstein, 2000; Mead and Bower, 2000). In other words, the healthcare professional needs to understand how the patient interprets their illness and work within this interpretation to facilitate an individualised care or treatment plan. Yet when a patient interprets their illness experience, they may use forms of language and metaphorical references that are not easily translated into healthcare language.

One medium that can be used to demonstrate the difference between a patient's interpretation of their illness and biomedical discourse is autobiography. Autobiographical or first person narrative accounts of a person's experience of illness present an opportunity for healthcare professionals to examine how the patient constructs this experience from memory (Power et al., 2012). From the patient's point of view, autobiography enables them to examine their memory of the experience to reconstruct it so that they can demonstrate their own personal meaning (Smorti et al., 2008; Shapiro, 2011). These meanings are often developed from the patient's own cultural perspectives, which may or may not conform to the accepted healthcare view of the illness (Hinton and Levkoff, 1999). Yet, these accounts can be considered 'authentic' because they represent how the patient has come to terms with their experience and how they give meaning to the course, progression and resolution of an illness (Collins, 2011).

This paper examines an autobiographical account of a woman's experience of postnatal psychosis. The account comes from what is considered to be the oldest autobiography in the English language, *The Book of Margery Kempe*, and presents the life of the eponymous woman, who lived from 1373 to approximately 1439. Margery's life story begins when she reconstructs her experience of what has been identified by medical historians as postnatal psychosis following the birth of her first child (Porter, 1988; Marland, 2004; Craun, 2005). Margery's state of mind has been discussed at length in the critical literature (Drucker, 1972; Ober, 1985; Porter, 1988; Harper, 1997; Craun, 2005). However, a detailed examination of her lived experience of postnatal psychosis and how this account informs the healthcare professional has not yet been undertaken. The aim of this study is to demonstrate the difference between the language of the healthcare professional and that of the patient, the differences between interpretations of the same experience and the challenges for the healthcare professional to see how a patient makes meaning of their experience of postnatal psychosis. If a healthcare professional understands the patient's view of the illness, a care or treatment plan can be developed that incorporates the patient's beliefs and values and is more likely to result in increased patient satisfaction and compliance with care and treatment (McCormack et al., 2010).

It should be noted that this paper does not intend to provide an historical context to a woman's experience of postnatal psychosis in the 15th century but it is, perhaps, more powerful because it was written before a biomedical explanation of postnatal psychosis was developed. The account is therefore used to explore how autobiographical accounts can assist today's healthcare professionals understand a person's unique experience of this condition.

## **Background**

Postnatal psychosis, also known as postpartum or puerperal psychosis, is a psychiatric emergency that occurs in the first two weeks following childbirth and affects one to two women per 1000 (Sit et al., 2006; Heron et al., 2008; Doucet et al., 2009). It significantly increases the risk of maternal suicide and infanticide (Rowan and Bick, 2007; Posmontier, 2010). The onset of postnatal psychosis is rapid and the condition is characterised by paranoid, grandiose or bizarre delusions, mood swings, confused thinking and disorganised behaviour that presents a dramatic change from pre-morbid functioning (Sit et al., 2006; Oates, 2008). The presentation of postnatal psychosis can be confused with postnatal

depression because it can share many of its clinical features; however, it can be differentiated by the presence of delusions, hallucinations, confusion, perplexity, or mania (Doucet, et al., 2009). Table 1 outlines the modern biomedical understanding of postnatal psychosis based on recent literature.

<b>Table 1: Summary of the characteristics of postnatal psychosis</b>	
Prevalence	<ul style="list-style-type: none"> <li>• 0.1-0.2% of women following childbirth</li> </ul>
Risk factors	<ul style="list-style-type: none"> <li>• Personal/family history of postnatal psychosis</li> <li>• Genetics</li> <li>• Hormonal changes</li> <li>• First pregnancy</li> <li>• Sleep loss</li> </ul>
Onset	<ul style="list-style-type: none"> <li>• Sudden, usually within two weeks of childbirth</li> </ul>
Symptoms	<ul style="list-style-type: none"> <li>• Mania or severe variations in mood</li> <li>• Delusions</li> <li>• Hallucinations: auditory, visual and olfactory</li> <li>• Bizarre behaviour</li> <li>• Severe depression</li> <li>• Confusion</li> <li>• Perplexity</li> </ul>
Management	<ul style="list-style-type: none"> <li>• Hospitalisation</li> <li>• Mood stabilising agents</li> <li>• Antipsychotic agents</li> <li>• Hormone therapy</li> <li>• ECT</li> <li>• Antidepressants (with caution)</li> </ul>
Long-term outcomes	<ul style="list-style-type: none"> <li>• 62% have non-postnatal episodes of bipolar disorder</li> <li>• 57% have further postnatal episodes</li> </ul>
<i>Adapted from: Brockington (1996); Sit (2006); Heron et al., (2008); Doucet et al., (2009)</i>	

A recent public inquiry in the UK has highlighted the need for greater recognition of postnatal psychosis. In a sample of 17 women who had committed suicide within six months of giving birth and had a diagnosis of a severe mental illness, eight were initially diagnosed as being anxious or having a moderate depression despite the recording of signs and symptoms of postnatal psychosis in their healthcare records (Oates and Cantwell, 2011). One reason for this lack of recognition could be that postnatal psychosis is not seen as a discrete condition but is viewed as either a manifestation of an underlying bipolar disorder, a severe form of depression or as a reoccurrence of a primary psychotic disorder such as schizophrenia (Posmontier, 2010). The condition is classified as postnatal if the onset of symptoms occurs in the six weeks following childbirth (Doucet et al., 2011). *The Diagnostic and Statistical Manual of Mental Disorders IV TR* and the *International Classification of Diseases 10* place postnatal psychosis under the general category of mood disorders and do not see it as a separate entity (World Health Organization, 1992; American Psychiatric Association, 2000).

If postnatal psychosis is viewed in the spectrum of mood disorders, rather than as a separate condition, its focus will remain with the mental health professional. Although mental health intervention is required once postnatal psychosis is diagnosed, there remains a distinct and important role for the midwife monitoring the woman following childbirth (Rowan and Bick, 2007; Posmontier, 2010). If the midwife assesses that the woman is showing early signs or symptoms of the condition, referral can be made to mental health services before the onset of the most serious manifestations (Doucet et al., 2009). Early intervention leading to a swift and accurate diagnosis does lead to better outcomes for the woman and the child because postnatal psychosis can have long term negative consequences for

the mother-child bond, resulting in further mental health problems for both (Robertson and Lyons, 2003; Sit et al., 2006; Noorlander et al., 2008; Boyce and Barriball, 2010).

Margery's account of the condition is an important tool for healthcare professionals. It presents a snapshot of the natural course of postnatal psychosis because it was written before any modern medical understanding or treatment was available. However, the account could be considered inaccessible to the modern researcher, as it does not use the language of modern biomedical discourse to describe the signs and symptoms of the condition. Margery explains her experience through a paradigm that informed her own worldview. As this worldview was predominantly Christian, she describes her experience in terms of Christian imagery. This becomes Margery's way of making sense of her lived experience of postnatal psychosis (Raingruber, 2009). Nonetheless, when this account is read against modern medical conceptions of the disease, it is possible to analyse her lived experience through the Christian imagery.

The text is written in the third person because at that time women were unlikely to be able to read or write, so Margery's life is dictated to a series of scribes (Windeatt, 2000). Although the question of how much Margery actually contributed to the writing of the book has been a source of continuing debate, many literary scholars now believe that internal evidence in the text shows that Margery had a great deal of editorial control (Johnson, 1991; Archibald, 2010). As such, the text has validated its description as an autobiography and is therefore a significant source for researchers to investigate postnatal psychosis from the patient's point of view.

The value of this exercise might be questioned by those who view illness through a biomedical position which favours a clinical method of identifying and treating specific conditions, thereby often reducing the patient's experience of illness to a set of signs and symptoms (Mead and Bower, 2000). Nevertheless, it must be recognised that the study of literature and other humanities-based research techniques are becoming more prevalent in medical and nursing education to demonstrate the importance of understanding how patients view their conditions (Frid et al., 2000; McKie, 2012). Patients' accounts of their illness experience found in literature can evoke an emotional response in the healthcare professional that is not accessed when illness is viewed through the more detached biomedical lens. Therefore these accounts act as powerful conduits through which healthcare professionals can access a process of reflection to consider their own practice against the patient's experience (Crawford et al., 2010). The value of studying patient experiences of illness found in literature is clear because it is a pathway through which the healthcare professional can develop empathy or the ability to understand how patients view their illness (Charon and DasGupta, 2011; Cunico et al., 2012). This occurs when the healthcare professional enters the patient's experience as they read the account of their illness (Dellasega et al., 2007).

## **Method**

### ***Research design***

This study used a qualitative research design based on a textual analysis approach.

### ***Data collection***

The data is collected from an extract from the opening chapter of *The Book of Margery Kempe*, written in approximately 1439, describing an episode of postnatal psychosis. The extract is taken from the following edition: Windeatt, B. (Ed.) (2000) *The Book of Margery Kempe: Annotated Edition*. Cambridge: Brewer. pp 52-56.

### ***Analysis***

Textual analysis is a process that enables researchers to analyse texts in isolation from their context to examine how a reader interprets what is written (Burnard, 1996; Miller and Alvarado, 2005; Wall, 2006). This is achieved by interrogating the text in a systematic manner by asking the text specific questions (Jefferies et al., 2012). These questions enable the reader to reflect on the specific text

and use their own reading to critique their healthcare practice against the recorded autobiographical experience of the patient (Stanley and Hurst, 2011).

In order to access Margery’s illness experience, her account was read against the modern biomedical discourse of postnatal psychosis using a scale adapted by Orbell et al. (2008) from the common-sense model of illness devised by Leventhal et al. (1992). This model was chosen because it was developed to assess levels of understanding of treatment options based on the dynamics of patient-doctor communication. The adaptation by Orbell et al. (2008) of this model is useful because it has been applied to both clinical situations and to literary texts in order to understand how a patient views their experience of illness (Orbell et al., 2008; Kaptein and Lyons, 2010). The scale provides the following domains that can be used to systematically interrogate the text: identity; causes; consequences; timeline; control (treatment); control (personal); coherence; and emotional representations (Orbell et al., 2008; Kaptein and Lyons, 2010). Table 2 gives a description of the scope of each of the domains of the common-sense model of illness. Various excerpts from the text are categorised into the relevant domains and interpreted by the researcher to show how a reader could come to understand the meaning of the text.

Table 2: Domains of patients’ perceptions of their illness		
	Domain	Description
1	Identity	Symptoms and labels a patient attributes to the illness experience
2	Cause	Attributions of the cause(s) of physical or mental signs and symptoms
3	Consequences	Patient’s belief about the outcome of the illness
4	Timeline	Perceptions about the length of the illness
5	Control (treatment)	Perceptions about how medical, psychosocial or other forms of treatment have affected the outcome
6	Control (personal)	Perceptions about the availability, efficacy and accessibility of a means of controlling the signs and symptoms
7	Coherence	Degree to which the patient perceives the illness to be clear and unambiguous
8	Emotional representations	Emotional responses associated with the signs and symptoms
<i>Adapted from: Orbell et al. (2008); Kaptein and Lyons (2010)</i>		

### **Ethics**

Ethics approval was not sought for this study, as the text is approximately 600 years old and is freely available and accessible to the public.

### **Results**

The text analysed in this study is the opening chapter of *The Book of Margery Kempe*, which describes her experience of postnatal psychosis. Although the account is short – 77 lines of prose – it contains a vivid account of the illness (Windeatt, 2000). As the text was written between the years 1436 and 1439, it is written in an archaic form of English, known to scholars as Middle English. However, for the purpose of this paper, the English has been translated into modern English by the authors (see Table 3 for modern English and Middle English text, accordance with modern medical discourse and domain from the common-sense model of illness). Extracts from the text are used to illustrate how Margery viewed her episode of postnatal psychosis, and they are cited in the text via page and line number based on the version edited by Windeatt (2000). The quotations are analysed using the domains of the patient’s perception scale described above.

**Table 3: Quotations from *The Book of Margery Kempe* with the translation into modern English and the original Middle English text**

Common-sense model of illness domain	Modern English	Original Middle English text	Healthcare interpretation of signs and symptoms	Reference in modern healthcare literature
<b>Identity</b>	Went out of her mind and was astonishingly afflicted and affected by spirits for eight-and-a-half months (p 54, lines 199-201)	Went owt of hir mende and was wondyrly vexed and labowryd wyth spyrytys half yer, viii wekys and odde days	Margery acknowledges that she was mentally ill for eight-and-a-half months	
.	And in this time she saw, as she thought, devils opening her mouth all inflamed with burning flames as if they would have swallowed her in, sometimes pawing at her, sometimes threatening her, sometimes pulling at her and dragging her both night and day during this time (p 54, lines 202-206)	And in this tyme sche sey, as hir thowt, develys opyn her mowthys al inflaumyd with brenny[n]g lowys of fyr, as thei schuld a swalwyd hyr in, sumtyme ramping at hyr. Sumtyme thret yng her, sumtym pullyng hyr and halyng hir bothe nygth and day duryng the forseyd tyme	Margery is describing both tactile and visual hallucinations. The hallucinations are also examples of delusions that have a religious basis	Sit et al. (2006) Heron et al. (2008) Oates (2008) Doucet et al. (2009)
	And also the devils screamed at her in a very threatening manner and demanded that she abandon her Christian faith and deny God, his mother (Mary) and all the saints in heaven, her good works and all good virtues, her father, her mother and all her friends (p 54, lines 206-210)	And also the develys cryed upon hir with greet thretyngys, and bodyn hir sche schuld forsake hir Crystendam, hir feyth, and denyin hir God, hys moder, and alle the seyntes in hevyn, hyr goode werkys and alle good vertues, hir fadyr, hyr modyr, and alle hire frendys	Margery is describing auditory hallucinations	Sit et al. (2006)
	She slandered her husband, her friends and her own self; she spoke many abusive and wicked words; she did not know virtue or goodness; she desired all wickedness; as the spirits tempted her to say and do, so she said and did (p 54-55, lines 210-214)	Sche slawndred hir husband, hir frendys, and her owyn self; sche spak many a reprevows worde and many a schrewyd worde; sche knew no vertu ne goodnesse; sche desired all wykkydnesse; lych as the spyrytys temptyd hir to sey and do, so sche seyde and dede.	Margery describes her behaviour in response to the hallucinations, which she believes is a dramatic change from her previous functioning	Sit et al. (2006) Heron et al. (2008) Oates (2008)
	And as a reminder of this, she bit her hand so forcefully that it (the scar) was seen afterwards all her life (p 55, lines 215-217)	And into wytnesse therof sche bot hir owen hand so violently that it was seen al hir lyfe aftyr	Margery had described that she attempted suicide on a number of occasions and the scar on her hand was a reminder of this	Sit et al. (2006) Oates (2008)
	And she tore her skin against her heart with her nails so violently, because she had no other instruments (p 55, lines 217-219)	And also sche roof hir skyn on hir body ayen hir hert wyth hir nayles spetowsly, for sche had none other instrumentys	Margery describes her attempts at self-mutilation. This could also be described as purposeless activity	Oates (2008)

**Table 3 (continued): Quotations from *The Book of Margery Kempe* with the translation into modern English and the original Middle English text**

Common-sense model of illness domain	Modern English	Original Middle English text	Healthcare interpretation of signs and symptoms	Reference in modern healthcare literature
<b>Cause</b>	And after she had conceived, she was afflicted with severe attacks of illness until the child was born. And with the difficulty she had in childbirth and the sickness before that, she despaired of her life, thinking she may not live (p 52, lines 177-180)	And aftyr that sche had conceived, sche was labowrd with grett accessys tyl the child was born and than, what for labowr sche had in chyldyng and for sekenesse goyng befor, sche dyspered of hyr lyfe, wenyng sche mygth not levyn	Margery describes a difficult pregnancy and childbirth. She also places the onset of the psychotic episode as being soon after childbirth	Sit et al. (2006) Heron et al. (2008) Oates (2008)
.	And then she sent for her priest, because she had a thing on her conscience which she had not revealed anytime before in her life (p 52, lines 180-182)	And than sche sent for hyr gostly fadyr, for sche had a thing in conscyens which sche had nevyr schewyd befor that tyme in alle hyr lyfe	Margery describes how thoughts of her unnamed sin perplexed her following childbirth	Sit et al. (2006) Heron et al. (2008) Oates (2008)
	Because she was always hindered by her enemy, the devil, always saying to her that while she was in good health she did not need to confess her sin, but could do penance by herself, and that all should be forgiven, for God is merciful enough (pp 52-53, lines 183-186)	And also the develys cryed upon hir with greet For sche was evyr lettyd be hyr enmy, the devel, evrymor seyng to hyr whyl sche was in good heele hir nedyd no confessyon, but don penawns be hirself alone, and all schuld be forovyn, for God is merciful inow	Margery describes possible earlier manifestations of auditory hallucinations	Sit et al. (2006) Heron et al. (2008) Oates (2008)
	And, when anytime she was sick or troubled, the devil said in her mind that she should be damned, because she has not been absolved of her sin (p 53, lines 189-191)	And, whan sche was any tym seke or dysesynd, the devil seyde in her mende that sche schuld be dampnyd, for sche was not schrevyn of that defawt	Margery again describes symptoms that could be seen as early signs of auditory hallucinations	
<b>Consequences</b>	Then this creature, the subject of this treatise, shall show how the mercy of Jesus in this part of her life, touched by the hand of our Lord with great bodily sickness, where through she lost her reason and wits for a long time until our Lord restored her again, as it shall be seen openly after (pp 42-43, lines 28-32)	Than this creatur, of whom thys tretys throw the mercy of Jhesu schal schewen in party in levying, towched be the hand of owyr Lord with grett bodily selenesse, wherthorw sche lost reson and wyttes a longym tyl ower Lord be grace restoryd her ageyn, as it schal mor openly be schewed aftyrward		
<b>Control (treatment)</b>	Except that she was tied up and kept forcibly restrained both day and night so that she might not have her will [to harm herself] (p 55, lines 219-21)	Saf sche was bowndyn and kept wyth strength bothe day and night that sche mygth not have hir wylle	She required containment and restraint to ensure that she did not harm herself	Sit et al. (2006) Heron et al. (2008)

**Table 3 (continued): Quotations from *The Book of Margery Kempe* with the translation into modern English and the original Middle English text**

Common-sense model of illness domain	Modern English	Original Middle English text	Healthcare interpretation of signs and symptoms	Reference in modern healthcare literature
<b>Control (treatment)</b>	He should not hand over the keys because they said she would give the goods away, as she knew not what she said, as they supposed (p 56, lines 241-243)	He schuld delyvyr hir no keys, for thei seyde sche wold but yeve away swech good as ther was, for sche wist not what sche seyde, as thei wende	Margery's behaviour is seen as unpredictable by her servants who advise that she should not be given access to the pantry	Sit et al. (2006) Heron et al. (2008) Oates (2008) Doucet et al. (2009)
<b>Control (personal)</b>	Our Lord Christ Jesus, ever to be trusted, worship be his name, never forsaking his servant in a time of need, appeared to his creature, who had forsaken him, in the likeness of a man, most dignified, most beautiful and most friendly that everyone can see with their eyes, dressed in a cloak made of purple silk, sitting at the bedside and looking on her with a blessed expression that strengthened her spirits (p 55, lines 224-231)	Owyr merciful Lord Chist Jhesu, evyr to be trosted, worshyped be hys name, nevyr forsakyng hys servawnt in tyme of need, aperyd to hys creatur which had forsakyn hym in lyknesse of a man, most semly, most bewtyvows, and most amiable that evyr mygth be seen wyth mannys eye, clad in a mantyl of purpyl sylke, syttyng upon hir beddys side, loking upon hir wyth so blyssyd a chere that sche was strengthyd in alle hir spyritys	A spontaneous remission indicating a good prognosis	Sit et al. (2006) Heron et al. (2008) Oates (2008) Doucet et al. (2009)



## **1. Identity**

The first analytic domain is categorised as Identity. It refers to the symptoms and the labels the patient attaches to the experience of illness. Margery, because she had no knowledge of modern concepts of symptoms, simply tells her reader that she:

*'Went out of her mind and was astonishingly afflicted and affected by spirits for eight-and-a-half months' (p 54, lines 199-201).*

Margery acknowledges that she has become insane, however she identifies that she is insane because she is troubled by spirits. She has placed the context of her insanity in Christian imagery.

The actual symptoms of her experience of 'going out of her mind' can be read as tactile and visual hallucinations, acknowledged symptoms of postnatal psychosis categorised in modern biomedical discourse (Sit et al., 2006; Heron, et al., 2008; Oates, 2008; Doucet, et al., 2009). But in Margery's own language these symptoms become an experience of being surrounded and taunted by devils as she interprets her condition in terms of Christian imagery:

*'And in this time she saw, as she thought, devils opening her mouth all inflamed with burning flames as if she would have swallowed her in, sometimes pawing at her, sometimes threatening her, sometimes pulling at her and dragging her both night and day during this time' (p 54, lines 202-206).*

Other psychotic symptoms described in terms of her Christian faith are auditory hallucinations (Sit et al., 2006):

*'And also the devils screamed at her in a very threatening manner and demanded that she abandons her Christian faith and denies God, his mother (Mary) and all the saints in heaven, her good works and all good virtues, her father, her mother and all her friends' (p 54, lines 206-210).*

Modern biomedical discourse states that women with postnatal psychosis are compelled to act on their hallucinations and delusions (Posmontier, 2010). In her own account, Margery demonstrates how her behaviour has changed as she is compelled to act on her auditory hallucinations, which she attributes to voices of devils:

*'She slandered her husband, her friends and her own self; she spoke many abusive and wicked words; she did not know virtue or goodness; she desired all wickedness; as the spirits tempted her to say and do, so she said and did' (pp 54-55, lines 210-214).*

The final description of Margery's experience of postnatal psychosis gives a vivid account of how she harmed herself. Firstly she says that she attempted suicide many times during this period (p 55, lines 214-215). Realising that if she did successfully kill herself she would be damned, she creates a permanent reminder of how close she came to this:

*'And as a reminder of this, she bit her hand so forcefully that it (the scar) was seen afterwards all her life' (p 55, lines 215-217).*

Margery also describes other acts of self-mutilation:

*'And she tore her skin against her heart with her nails so violently, because she had no other instruments' (p 55, lines 217-219).*

## **2. Cause**

The cause of Margery's experience of illness, or the second domain of the patient's perception scale, is firmly linked to pregnancy and childbirth. Her autobiography begins when she tells the reader that she married a honourable merchant when she was about 20 years old and quickly fell pregnant, but

both the pregnancy and childbirth were difficult experiences for Margery:

*'And after she had conceived, she was afflicted with severe attacks of illness until the child was born. And with the difficulty she had in childbirth and the sickness before that, she despaired of her life, thinking she may not live'* (p 52, lines 177-180).

Margery describes her state of mind following childbirth. In modern biomedical language Margery could be exhibiting the early signs of postnatal psychosis as she reports her growing fears that she might not survive. In biomedical terms, Margery is showing signs of being perplexed (Sit et al., 2006; Heron et al., 2008; Oates, 2008; Doucet et al., 2009). As Margery cannot understand her condition from a modern biomedical point of view, she depicts this perplexity in terms of her Christian worldview. In the medieval period preparation for death required reconciliation with Christ by confessing your sins and receiving absolution from a priest (Aries, 1974; Binski, 1996). She is troubled about the state of her soul, as she has not been absolved of an unnamed sin:

*'And then she sent for her priest, because she had a thing on her conscience which she had not revealed anytime before in her life'* (p 52, lines 180-182).

However, Margery signals that her concerns have increased since the birth, as she now believes that the devil convinced her not to confess her sin in the past:

*'Because she was always hindered by her enemy, the devil, always saying to her that while she was in good health she did not need to confess her sin, but could do penance by herself, and that all should be forgiven, for God is merciful enough'* (pp 52-53, lines 183-186).

Two issues are raised here: first, that Margery could be experiencing auditory hallucinations as she describes how the devil led her into a false state of security about her sin in the past; and second, that following the birth her anxiety, or perplexity, about this sin has increased. She no longer believes that private penance will absolve this sin, now she believes that she requires confession and absolution from a priest. Margery articulates this fear again and links it to her experience of illness, possibly denoting further evidence of auditory hallucinations when she says:

*'And, when anytime she was sick or troubled, the devil said in her mind that she should be damned, because she has not been absolved of her sin'* (p 53, lines 189-191).

In Margery's eyes, whether reasonable or not, the cause of her postnatal psychosis is her unwillingness to confess an unnamed sin while she is in good health. Furthermore, the event that drives Margery into insanity, as she describes it, is that the priest who attends her is hasty and begins to reprimand her before she had finished confessing her sin (p 54, lines 195-197). In Margery's mind, not being able to complete her confession means that her fear of death is compounded by her recent experience of her hallucinations, which she describes as the devil talking to her. Margery is, therefore, extremely anxious about the state of her soul and the possibility of facing eternal damnation. It is this fear that informs the content of her hallucinations.

### **3. Consequences**

The third domain, or consequences, asks how the patient makes meaning of the illness experience once it has been resolved or cured. In later life, when Margery is dictating this episode of postnatal psychosis to her scribe, she is clear about the personal meaning. In the prologue to the autobiography she says:

*'Then this creature, about whom this treatise through the mercy of Jesus shall show in the part of her life, touched by the hand of our Lord with great bodily sickness, where through she lost her reason and wits for a long time until our Lord restored her again, as it shall be seen openly after'* (pp 42-43, lines 28-32).

To Margery this episode can only be interpreted in Christian terms; she says that her illness is the consequence of her disobedience to God. The episode of postnatal psychosis becomes a means of correction. The psychotic symptoms, which so vividly demonstrate the torments that await her in hell, act to remind Margery that she cannot deviate from the will of God.

#### **4. Timeline**

The fourth domain asks for a timeline of the illness experience. As discussed earlier, Margery says her illness lasted eight-and-a-half-months and began shortly after the birth, when she believed that she might die. The time between the birth and onset of psychotic symptoms is not given in the text.

#### **5. Control (treatment)**

This domain asks how the patient perceives the treatment received for the illness in terms of medical or psychosocial factors. In Margery's account of her postnatal psychosis, the focus of treatment by her attendants is to control her behaviour so that she does not harm herself. Therefore, Margery reports that she was physically restrained:

*'Except that she was tied up and kept forcibly restrained both day and nights that she might have her will [to harm herself]'* (p 55, lines 219-21).

Other clues in the text demonstrate efforts to control Margery's behaviour. When describing her hallucinations, Margery tells her reader that devils opened her mouth with burning flames as if she would swallow them in (p 54, lines 202-204). This could be interpreted as a description of Margery's attendants attempting to give her some form of medication. Later in this description the reader is told that these devils pulled and dragged her (p 54, line 205); again, this could be a reference to the attendants' attempts to restrain and modify Margery's behaviour.

The final clue describing Margery's treatment is found after the postnatal psychosis has resolved. She asks her husband for the keys to the buttery (or pantry) but the attendants advise against this:

*'He should not hand over the keys because they said she would give the goods away, as she knew not what she said, as they supposed'* (p 56, lines 241-243).

Her attendants have usurped Margery's position as mistress of the household. They make it clear that they believe that her behaviour has been so unreasonable that she is incapable of performing the role that she held before her postnatal psychosis.

#### **6. Control (personal)**

In contrast to the previous domain, this domain looks at how the patient comes to understand their illness experience and learns to control the symptoms. Having experienced restraint, and possibly the forced administration of medication, as the only treatment measures available from her attendants, Margery explains how she finds her own method of controlling her symptoms as she reports on what she believes was a visit from Christ, described in vivid terms:

*'Our Lord Christ Jesus, ever to be trusted, worship be his name, never forsaking his servant in a time of need, appeared to his creature, who had forsaken him, in the likeness of a man, most dignified, most beautiful and most friendly that everyone can see with their eyes, dressed in a cloak made of purple silk, sitting at the bedside and looking on her with a blessed expression that strengthened her spirits'* (p 55, lines 224-231).

What is significant about Margery's belief that Christ had visited her was that it gave her a method of controlling her symptoms of postnatal psychosis. Christ reminds Margery that although she had forsaken him, he had not forsaken her (p 56, line 232). This reminder of Margery's obligation to Christ has an immediate effect as her wits become stable again (p 56, line 237). Margery has responded to this illness experience by framing it in Christian imagery – she sees her symptoms of postnatal

psychosis as a foretaste of hell and its torments. Therefore, a reminder of Christ's presence in her life calms her fears and empowers her to control her own hallucinations or, as she describes it, a method of combating this devilish presence in her life.

### **7. Coherence**

Margery's account of her postnatal psychosis was dictated to her scribe approximately 40 years after the event occurred. The experience has been fully integrated into Margery's consciousness and although it is explained through Christian imagery, it is possible to ascertain how Margery viewed the cause, progression, treatment and resolution of her illness.

### **8. Emotional representation**

Although the account does not discuss any overt emotions experienced by Margery during her postnatal psychosis, the distressing nature of Margery's experience becomes explicit in the description of her symptoms and treatment. She tells her readers that she was surrounded by devils who forced her to say and do things that she considered wicked. These included slandering and abusing her husband and friends, denying her faith, attempting suicide and self-mutilating. She also describes how she was tied down and restrained throughout this period of illness and lost her position in her household as the mistress. All these events would take an emotional toll on Margery as the patient and possibly on the reader.

### **Discussion**

Although the episode of postnatal psychosis found in *The Book of Margery Kempe* is only 77 lines long, it gives a striking picture of a woman's descent into postnatal psychosis and her recovery from this illness. To modern healthcare professionals this description presents an almost unique opportunity to view a self-portrait of the experience of postnatal psychosis from a woman's point of view and come to understand how she might make sense of the experience without access to biomedical language (Porter, 1988). This is a valuable exercise because healthcare professionals can use autobiographical material to reflect on how care plans can be constructed to include the needs and wants of the patient and ensure greater patient satisfaction and compliance (McCormack et al., 2010). The episode was analysed using the eight domains of the common-sense model of illness (Orbell et al., 2008; Kaptein and Lyons 2010). This discussion will also demonstrate how knowledge of Margery's view of her experience of illness can be incorporated into a more person-centred care plan.

The first three categories – identity, cause and consequence – demonstrate Margery's reconstruction of her illness experience from memory. She says that at this time she went out of her mind and describes her psychotic symptoms in terms of devils taunting her and encouraging her to say and do things that she found wicked. However, Margery rationalises her illness in terms of her Christian faith and blames herself for the onset of symptoms because she has allowed the devil to convince her that she need not follow the precepts of her faith by seeking absolution for her unnamed sin through confession. This aspect of life is very important because many years later, when Margery is an elderly woman, this episode serves to remind her of the importance of maintaining her faith. A scar from where she bit herself during her illness serves as a physical reminder of the reality of her illness.

In terms of modern biomedical discourse of postnatal psychosis, Margery's description conforms to the course of the illness described in modern healthcare literature (Brockington, 1996; Sit et al., 2006; Heron et al., 2008; Doucet et al., 2009; Oates and Cantwell, 2011). The onset of Margery's symptoms occurs following the birth of her child and although the text does not reveal the exact time frame, the fact that Margery has mentioned her difficult pregnancy and her fear of dying following childbirth links the two events (Sit et al., 2006). Also Margery's descriptions of visual, tactile and auditory hallucinations, described in terms of Christian imagery, are consistent with the signs and symptoms of postnatal psychosis found in current healthcare literature (Heron, et al., 2008; Posmontier, 2010). Finally, her self-reported suicide attempts and self-mutilation are consistent with modern biomedical discourse (Posmontier, 2010; Oates and Cantwell, 2011).

Margery sees her behaviour during this period as being out of character by emphasising that she was influenced by the devil. In biomedical discourse Margery's response to her psychotic symptoms would be classified as bizarre (Sit et al., 2006). However, if a more holistic and patient-centred approach had been taken when her fears of damnation became known, her care planning could have encompassed her spiritual needs, such as ensuring that she was able to make a full confession to relieve her anxieties. This may have relieved Margery's agitation and reduced her risk of attempting suicide and other self-mutilating behaviours.

A point of interest in this description of Margery's experience of postnatal psychosis is the absence of the child, as her account does not give any information about her life as a mother or the care of her child. One recent qualitative study of women's experience of this condition reported that women felt a sense of guilt and loss when they reflected on their illness experience because they could not care for their child and in some cases even became unaware that they had a child (Robertson and Lyons, 2003). The absence of the child in Margery's account of her illness experience perhaps draws attention to how the bond between the mother and child is disrupted by postnatal psychosis, leading to lifelong consequences for both. Early detection of psychotic symptoms and the early provision of treatment following childbirth can reduce the disruption to the mother-child bonding process (Doucet et al., 2009). In Margery's account of her illness, she describes how her view of the state of her soul changes as her fear of death grows. Her preoccupation with confession could mark an early sign of the onset of her psychosis. With skilful interviewing techniques based on a patient's account of what they are feeling and experiencing, a healthcare professional could detect these prodromal symptoms and introduce treatment early, thereby potentially preventing the substantial disruption to the mother-child relationship that Margery seems to have experienced.

The next three categories, namely timeline, control (treatment) and control (personal), open a window on the treatment she received during the episode. Margery's episode of postnatal psychosis reportedly lasted eight-and-a-half-months and spontaneously resolved following what she describes as a visit from Christ. Today, treatment with antipsychotic medication and mood stabilisers is instituted as soon as postnatal psychosis is diagnosed to reduce the disruption to the mother-child bonding process (Posmontier, 2010). Therefore, the modern literature does not discuss the issue of spontaneous recovery. However, in 1801 the male midwife Thomas Denman wrote in his observations of postnatal psychosis that:

*'The instances of its continuing more than six months are very rare; and there is scarcely one to be found that did not ultimately recover'* (Denman, 1801, p 496).

Denman qualifies this statement by reminding his readers that if a woman lives she will recover her faculties but many die from exhaustion caused by agitation.

Margery's description of her episode of postnatal psychosis suggests that she may have presented to her attendants as agitated and difficult to manage. Any effort at treatment or care was directed at controlling this behaviour. Margery reports that she also attempted suicide and self-mutilated and because of these behaviours she says that she was physically restrained night and day. The attendants base their decisions about treatment on their observations of Margery's behaviour. They advise Margery's husband not to give her the keys to the pantry after she has requested them. Their focus is to control Margery's behaviour, rather than to work with her in a person-centred manner to enable her to find solutions that help her control her symptoms. Margery's response to these treatment measures is an exacerbation in her psychotic symptoms because she describes being pulled and threatened by 'devils'. She is, possibly, describing the physical efforts of her attendants to manage her.

This description of the treatment Margery received demonstrates how the relationship between a patient and the healthcare professional can deteriorate if the patient's understanding of their illness is

not incorporated in their care plan. When the focus of care is centred on managing signs and symptoms based on a biomedical approach to the patient, rather than focusing on developing a patient-centred and therapeutic relationship that seeks to work with the patient to manage their illness, the approach to care is not holistic and may not comply with the patient's needs and wants (McCabe, 2004; Berwick, 2009).

The spontaneous resolution of her illness following her perceived vision of Christ is in line with historical studies of postnatal psychosis, which demonstrate that in the absence of organic disease, most women recovered usually after a period of six months in hospital (Protheroe, 1969). However, it also demonstrates the value of working with the patient after coming to understand how they view their illness (Hinton and Levkoff, 1999; Shapiro, 2011). Margery credits her recovery to Christ and, therefore, spends the rest of her life in what she perceives as his service. What sets Margery's account of her visit from Christ apart from the treatment she describes from her attendants is that she believes that Christ has given her a method of controlling her hallucinations. Although her encounter with Christ is another example of visual and auditory hallucinations in biomedical terms, this hallucination sought to calm Margery's fears rather than exacerbate them. Margery sees this encounter as therapeutic because it empowered her to find her own solutions to deal with her illness. Rather than outside forces attempting to control her behaviour by physically restraining her, Christ reminds her of the importance of her spiritual life and how it can help her control hallucinations that frighten her. Therefore, rather than taking a custodial view where the emphasis is on restraining the patient, Christ's visit represents a therapeutic relationship to help the patient understand their illness and develop skills to manage symptoms, resulting in a reduction in anxiety and agitation. This enables Margery to take greater control of her own activities of daily living and resume her former duties in her household.

The final two domains, identified as coherence and emotional representations, require the researcher to make a value judgement about how they read the text. Margery has given a coherent account demonstrating how she views her illness. She interprets the experience of illness from a Christian standpoint and articulates what she believes is the cause, progression, treatment and resolution of the illness. This, as is shown, can be mapped on to a modern biomedical understanding of postnatal psychosis thereby clarifying the difference between a patient's experience of illness and a description of the biomedical interpretation of the illness. Margery's emotional response to this episode is not explicitly described; however her description highlights the terrifying nature of her hallucinations and her treatment at the hands of her attendants.

### **Conclusion**

*The Book of Margery Kempe* presents an opportunity for researchers and clinicians to investigate how a patient sees an episode of postnatal psychosis. Although this account was written in the first half of the 15th century and uses Christian imagery to describe the experience, when it is read through the lens of a tool such as the domains of the common-sense model of illness, the patient's lived experience of illness is visible.

Margery's experience of illness is relevant to the modern healthcare professional because it shows how damaging a care plan that does not take the patient's view into account can be. Rather than basing care on a biomedical model that aims to control signs and symptoms, working in partnership with the patient empowers the patient and enables them to develop strategies to manage their symptoms, leading to a speedier recovery. Furthermore, this approach can ensure that the disruption to the bonding process between the mother and child caused by postnatal psychosis can be reduced, thereby greatly lessening the long-term effects of the condition.

### **Implications for practice**

This autobiographical account speaks to the modern healthcare professional about the misery caused by postnatal psychosis if it is not recognised and treated in a timely manner. It offers a reminder that listening to the patient's story and developing a person-centred approach to care enables the patient

to develop their own solutions and strategies to manage their illness. If this approach is not taken, the patient may become increasingly fearful and unresponsive because the healthcare professional has not taken the opportunity to investigate the patient's needs and wants. Margery's account of her episode of postnatal psychosis emphasises that although the patient may express their experience of illness in language that is far removed from the biomedical discourse of the healthcare professional, being able to interpret the patient's understanding of their illness is a crucial component of developing an individualised and person-centred care plan.

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