A Thesis Submitted for the Degree of PhD at the University of Warwick

The transition from hospital to community living for mental health patients and carers

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ADASS	Association of Directors of Adult Social Services
ASSIA	Applied Social Sciences Index and Abstracts
BPS	British Psychological Society
CASP	Canadian Association for Suicide Prevention
CI	Confidence Interval
DoH	Department of Health
DSH	Deliberate Self Harm
DSM	Diagnostic and Statistical Manual of mental disorders
HR	Hazard Ratio
ICD	International Classification of Diseases
IPA	Interpretative Phenomenological Analysis
MHA	Mental Health Act
NHS	National Health Service
NIMH	National Institute of Mental Health
NIMHE	National Institute for Mental Health in England
NMHDU	National Mental Health Development Unit
NPSA	National Patient Safety Agency

ONS	Office for National Statistics
OR	Odds Ratio
STROBE	STrengthening The Reporting of OBservational studies in Epidemiology
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

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Declaration

This thesis has not been submitted for any other degree or to any other institution and is a record of original work carried out by me. The thesis was conducted under the academic and clinical supervision of Jo Kucharska (Clinical Psychologist, Coventry University), Dr Adrian Neal (Clinical Psychologist) and Dr Vicky Hancock (Clinical Psychologist). The original idea for this work was my own and followed discussions with the supervisors named above. The validity of my coding was undertaken by a colleague and by the named supervisors, all of whom are familiar with Interpretative Phenomenological Analysis. The named supervisors also read drafts of the chapters. Apart from the collaborations stated, all the material presented in this thesis is my own work.

Summary

This thesis explores the transition from hospital to community living for mental health patients and carers. This period presents a number of challenges and risks for patients and the support from family members throughout this period is invaluable. Through further exploration of the discharge process and period, this thesis considers how both patients and carers can be better supported to manage the challenges and increase the likelihood of a successful transition.

The first paper is a systematic literature review investigating the predictors of suicide up to a year after discharge from mental health inpatient services. After database and manual searches were complete, thirteen studies met inclusion criteria and were reviewed and critically evaluated. Despite inconsistent findings across studies, the review identified some predictors of post-discharge suicide which have been replicated within and across cultures. Clinical implications in relation to thorough discharge planning and maintaining continuity of care are discussed.

The second paper reports on a qualitative exploration of family members' experiences of the discharge process from inpatient mental health services. Six family members were recruited and interviewed using a semi-structured method. The data was analysed using Interpretative Phenomenological Analysis. The three phenomenological themes emerging from participants' accounts indicated that the discharge process was characterised by isolation, fear and exhaustion. The themes are discussed, explored and considered in relation to how services can increase carers' involvement and strengthen their position in the discharge process.

The final paper reflects on insights into the world of carers gained through the research process, with a focus on loss and grief in caring. Comparing the processes of therapy and research, the paper considers how research offered greater freedom to 'hear' experiences and the potential advantages of transferring these reflections to the therapy room.

Overall word count: 19 351

Chapter One: Literature Review

Predictors of suicide within a year of discharge from inpatient mental health services: A systematic literature review

In preparation for submission to *Clinical Psychology Review* (see Appendix A for Author Instructions)

Overall chapter word count (excluding tables, figures and references): 8 036

1.1. Abstract

Objective: Those who are discharged from psychiatric inpatient care are at increased risk of suicide. The aim of this systematic review is to investigate predictors of suicide in the year after discharge.

Methods: PsycINFO, ASSIA, PsycARTICLES, Social Sciences Abstracts and Sociological Abstracts, Medline (OVID), Scopus and Web of Science were searched for all dates until the beginning of May 2013. Citation and reference list searches of key articles were also carried out. Thirteen articles met inclusion criteria (studies investigating predictor variables in a sample of patients who committed suicide within one year of discharge from an inpatient mental health setting).

Results: Factors most robustly associated with post-discharge suicide were: history of self-harm, diagnosis of an affective disorder, work related stress, break in follow-up care and missed appointments after discharge.

Conclusions: Despite inconsistencies in findings across studies, this review has identified some predictors of post-discharge suicide which are well-replicated within and across cultures. However, due to limitations within the reviewed studies, these conclusions remain tentative. This review highlights the need to enhance the support and follow-up of patients through thorough discharge planning and continuity of care. Despite considerable challenges in researching this area, the value in expanding our understanding of post-discharge suicide remains.

Key words: *suicide, discharge, discharge planning, continuity of care, psychiatric hospital, inpatient*

1.2. Introduction

1.2.1. Suicide and mental health

Every year, almost one million people across the world commit suicide (World Health Organisation (WHO), 2012). Despite a reduction in the UK over recent years, the suicide rate in 2011 was the highest since 2004 (Office for National Statistics (ONS), 2013). The publication of the Suicide Prevention Strategy (Department of Health (DoH), 2012) marked the beginning of a new drive to reduce “the avoidable toll of suicide in England” (2012, p. 4). One of its objectives is to reduce the rate of suicide among high-risk groups. Approximately 25% of individuals who commit suicide are known to mental health services prior to death (Windfuhr & Kapur, 2011), and as such are one of the high-risk groups targeted.

1.2.2. Suicide and psychiatric inpatient care

Among those under the care of mental health services, psychiatric inpatients are at particularly high risk of suicide, both during their admission and soon after discharge (Kapur *et al*., 2013). Studies in the UK, Denmark, Singapore and Hong Kong show that the risk of suicide is up to 200 times higher than that of the general population in the first weeks after discharge (Meehan *et al*., 2006; Qin & Nordentoft, 2005; Thong, Su, Chan & Chia, 2008).

On the basis of the high suicide risk amongst inpatients, a number of initiatives have been implemented to improve quality of care and reduce suicide (Canadian Association for Suicide Prevention (CASP), 2004; The Joint Commission, 2007; National Patient Safety Agency (NPSA), 2009; Hampton, 2010). Measures have primarily focused on improving the safety of the ward environment or reducing unauthorised absences (DoH, 2000). The success of these prevention strategies seems to be supported by a recent UK longitudinal study, which reported that, between 1997 and 2008, inpatient suicide fell by up to 31% (Kapur *et al*., 2013).

Although inpatient suicide now seems to be less common, Kapur *et al*. (2013) found that the rate of post-discharge suicide[1] increased by 19% between 1997 and 2008. This increasing trend was also identified by Hoang, Stewart and Goldacre (2011) with respect to discharged patients with schizophrenia and affective disorder. Kapur *et al*. suggest a number of potential explanations for the increase, such as a transfer of risk from inpatient settings to post-discharge due to earlier discharge from hospital. As yet there is no clear understanding, but as Kapur *et al*. recommend, these findings “warrant further exploration” (2013, p. 69).

1.2.3. Previous investigations of the post-discharge period

Current understanding of the post-discharge period is primarily based on quantitative studies investigating possible predictors of suicide within a year of discharge. Therefore making sense of this emerging evidence offers an opportunity for “further exploration” of this increasingly high-risk period (Kapur *et al*., 2013, p. 69).

Two previous literature reviews (Troister, Links & Cutcliffe, 2008; Large, Sharma, Cannon, Ryan & Nielssen, 2011) have attempted to synthesise the findings from studies investigating predictors of suicide within a year of discharge. Troister *et al*. (2008) from Canada reviewed 28 articles published up to 2006. Large *et al*. (2011)

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[1] Suicide up to a year after discharge from inpatient care

based in Australia conducted a meta-analysis reviewing thirteen controlled studies published up to 2010.

While these reviews offer some further understanding about post-discharge suicide, there are crucial gaps and methodological weaknesses which limit the reliability and utility of their findings. Troister *et al*.'s (2008) review lacks the clarity and detail required for a systematic review and it is unclear which risk factors relate specifically to the post-discharge period, due to the inclusion of studies exploring inpatient suicide. In Large *et al*.'s (2011) meta-analysis, study quality was not thoroughly assessed and, on closer scrutiny, two of the studies included (Pokorny, Howard & Kaplan, 1976; Yim *et al*., 2004) did not meet the inclusion criteria. These limitations therefore warrant a further investigation of the literature.

1.2.4. Rationale

Reducing suicide rates among those in contact with mental health services is one of the government's priorities (DoH, 2012). Within this population, the high and increasing rate of suicide in the post-discharge period (Kapur *et al*., 2013) highlights the need for further investigation, with a particular focus on the applicability of findings to the UK mental health system.

1.2.5. Aims of the review

The aims of this paper are to:

- Systematically review and summarise the evidence from all studies investigating factors associated with suicide in the first year after discharge from psychiatric inpatient care.

- Consider the evidence in the context of its utility in informing the management of those who are discharged from inpatient mental health care.
- Assess the quality of the research reviewed and make recommendations for future research.

1.3. Method

1.3.1. Search strategy

A systematic literature search was conducted in October 2012 and repeated early May 2013, using the following electronic databases: PsycINFO, Applied Social Sciences Index and Abstracts (ASSIA), PsycARTICLES, Social Sciences Abstracts and Sociological Abstracts, Medline (OVID), Scopus and Web of Science. Search terms were developed from preliminary searches of relevant existing literature. The search terms therefore specified the:

- Outcome (*suicide*)*
- Timing of outcome (*"post discharge*"* OR *postdischarge*)*
- Service received prior to outcome *("mental health inpatient service*"* OR *"inpatient service*"* OR *"inpatient setting*"* OR *"psychiatric hospital*")*

*(N.B. * represents truncation to capture variation in the terminology)*

The search was not restricted to a particular time frame, although studies published after the beginning of May 2013 were not considered, due to the completion deadline of this review.

An initial eligibility sort was carried out using the title followed by the abstract, referring to the selection criteria (see section 1.3.2). Full text copies of all potentially suitable articles or those requiring a more detailed investigation were then reviewed against the inclusion criteria.

Citation searches of all articles meeting the inclusion criteria were conducted using the Web of Science *cited reference search* function. The reference lists of all selected articles were then searched, followed by related literature reviews and relevant journals.

1.3.2 Selection criteria

Table 1.1 details the selection criteria used for assessing the relevance of retrieved articles.

Table 1.1 Inclusion and exclusion criteria

Inclusion Criteria	Published in a peer reviewed journal
	Investigates possible suicide predictors in a sample of patients (defined in this review as more than one) who had committed suicide within one year after being discharged from an inpatient mental health setting. *(N.B. 'discharge' defined as the point when a patient leaves hospital and either returns home or to another appropriate community setting, with no plans to return to hospital).*
Exclusion criteria	Paper is a review, commentary, discussion piece or legal paper
	Paper is not written in English
	The study utilises a case study design
	The sample is exclusively children, adolescents or older people (aged 60 or over)
	A mix of patients who committed suicide during and after discharge are included
	All suicide cases occurred beyond a year post-discharge
	Some or all of the patients attempted suicide or engaged in other types of suicidal behaviour
	Some or all of the patients were discharged from non-psychiatric wards
	The study reports suicide *rates* only.

1.3.3 Systematic search results

The initial searches resulted in the retrieval of 645 articles in total. After duplicates were removed, a total of 368 unique articles remained. These were reviewed by title and abstract leading to the exclusion of 319 articles. The remaining 49 articles were evaluated in full and nine of these met the inclusion criteria. A further four articles were identified through manual searching. Therefore in total thirteen articles were reviewed. Figure 1.1 illustrates this process and details the justification for excluding articles.

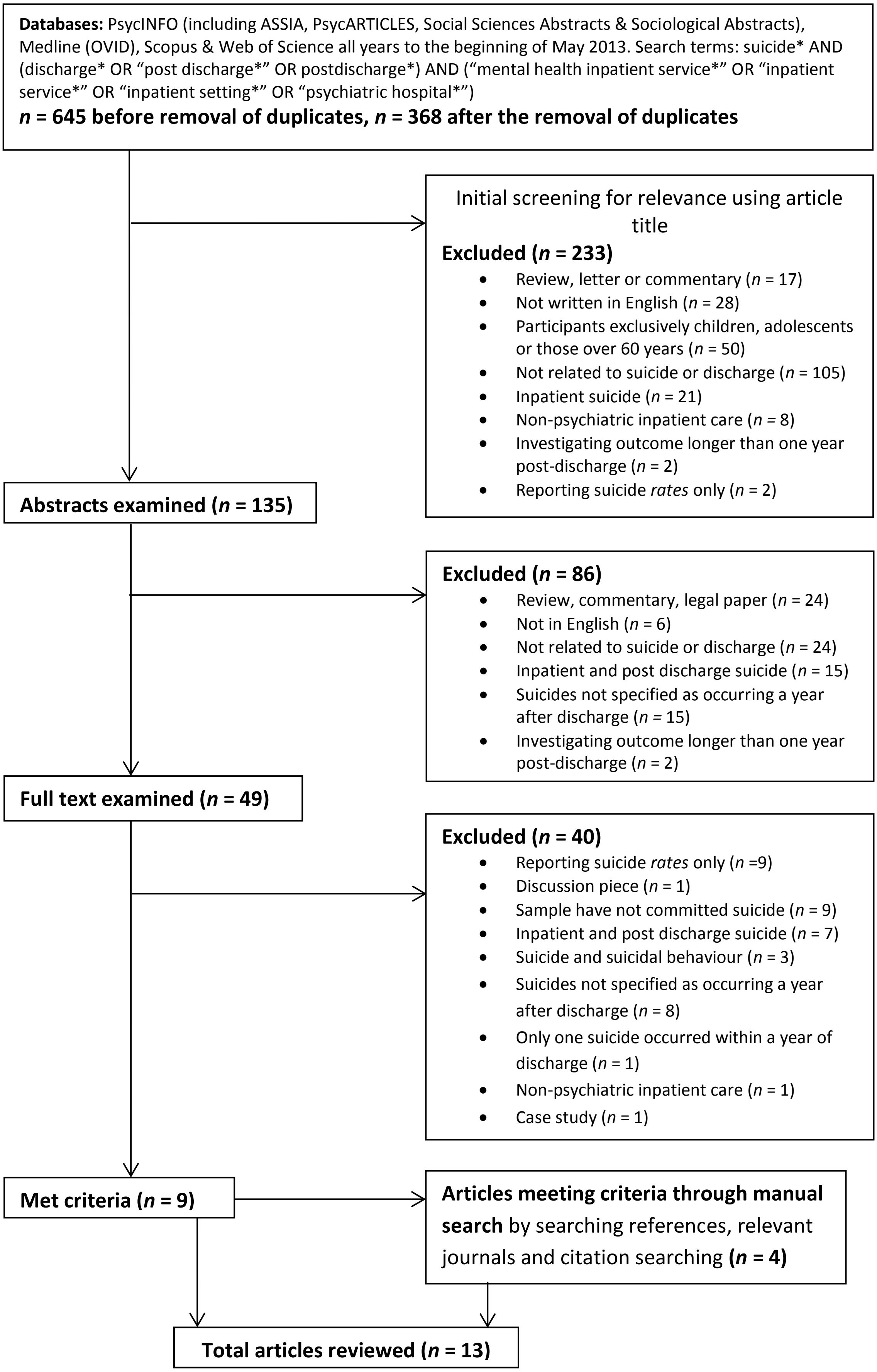

Figure 1.1 Systematic selection process

1.3.4 Assessment of quality

Following the systematic search, the thirteen retrieved articles were assessed and rated against a quality checklist devised by the first author (see Appendix C). In developing the checklist, recommendations made by Sanderson, Tatt and Higgins (2007) and the STrengthening The Reporting of OBservational studies in Epidemiology (STROBE) statement (von Elm *et al*., 2008) (see Appendix B) were referred to closely. Additionally the measures of quality adopted by Large *et al*. (2011) were incorporated. The quality assessment was completed using a set of notes to increase consistency (see Appendix D). To assess the reliability of the checklist, six (46%) of the included studies (first six when ordered alphabetically) were rated independently by a second reviewer (R.L). Cronbach's alpha was .972 indicating a high level of agreement.

1.3.4.1. Findings

The articles scored between eight and twenty-three out of thirty on the quality checklist and the median score was nineteen. This indicates that despite variability in quality across the studies, in general a number of the quality criteria were met. Therefore none of the retrieved studies were excluded on the basis of quality. However the assessment process highlighted a number of factors impacting on the quality of studies included in this review, as summarised below.

A number of studies used large population-based datasets which were representative of particular countries or regions, thereby avoiding selection bias. Despite this, some individual variables comprised only a small number of the whole sample and therefore may have held inadequate power to identify associations (e.g. Yim *et al*. 2004). Suicide cases had generally been determined on the basis of International Classification of Diseases (ICD) codes. Despite this, the challenge of classifying suicide is a frequently raised concern (Bohnert *et al*., 2013), indicating that the misclassification of suicide is quite possible.

The data available to analyse was limited in numerous ways. Often specific clinical variables were missing from databases, limiting the ability to recognise potential confounding factors (e.g. Lee & Lin, 2009). There was a potential recall bias in those studies that collected clinical information from informants after suicide had occurred (e.g. Hunt *et al*., 2009). Blinding was also not possible in those studies that collected clinical data by examining medical records (e.g. McKenzie & Wurr, 2001), although some studies (e.g. King *et al*., 2001) made efforts to limit this potential bias by using pro formas to guide the extraction of data.

Ten of the reviewed studies were controlled in an effort to balance confounding factors. While the matching criterion was well reported, the precision with which cases and controls were matched varied. Three studies were uncontrolled and therefore the conclusions drawn need to be treated more tentatively due to the potential confounding effects.

The reporting of statistical analysis varied in quality but was generally thorough and clear. Most, but not all studies controlled for the effect of confounding variables by entering them into regression analyses and reporting the adjusted odds ratio (OR). Some studies (e.g. Hoffman & Modestin, 1987; Modestin & Schwarzenbach, 1992) relied on less sophisticated techniques such as a chi-squared test or a two-tailed test.

1.4. Results

The thirteen studies included in this review are summarised in Appendix F. All studies investigated predictors of suicide within a year of discharge from psychiatric inpatient care, with some (e.g. Tseng, Chang, Liao, Chen & Lee, 2010) limiting the time period between discharge and suicide to 60 or 28 days. Most adopted a case-control design, using a sample of discharged survivors as the control group. Three of the studies were located in the United Kingdom (UK), four in other European countries, five in China and one in the United States of America (USA).

Suicide cases were generally identified through linking coroners' records or death certificates to an electronic hospital database. Suicide cases comprised deaths coded as 'suicide' according to the ICD and often those coded as 'undetermined'/'open verdict' as well. The number of suicide cases included in each study ranged from 19 (Pokorny *et al*., 1976) to 3846 (Pirkola, Sohlman, Heila & Wahlbeck, 2007). Most studies excluded patients whose suicide and discharge dates were the same to ensure that inpatient suicides were not included.

Suicide cases and surviving controls were compared according to a range of different variables. However, the variables could be clustered into the following four categories of suicide predictors:

- Socio-demographic
- Historical

- Clinical
- Service organisation and delivery

Findings in relation to each of these categories will be synthesised, analysed and critiqued in turn, to consider the most reliable and valid predictors of suicide during the high risk period after discharge.

1.4.1. Socio-demographic predictors of suicide within a year of discharge

1.4.1.1. Age

None of the studies that reported on the association between suicide and age found a difference in age distribution between cases and controls (Hunt *et al*., 2009; Hoffman *et al*., 1987; Lee *et al*., 2009; Lin, Lee, Kuo & Chu, 2008). However, Lee *et al*. (2009) and Lin *et al*. (2008) used age as a matching criterion, which is likely to explain this finding.

1.4.1.2. Gender

Hunt *et al*. (2009) found that male gender was an independent predictor of suicide in their multivariate regression model (OR=2.2). Although a number of studies found that men tended to dominate the suicide group, often the differences in the number of male and female cases of suicide were not significant (Tseng *et al*., 2010; Hoffman *et al*., 1987; Lee *et al*., 2009; Lin *et al*., 2008).

In contrast, Pirkola, Sohlman & Wahlbeck's (2005) findings indicate that females may be more at risk immediately after discharge, as this study reported that more females committed suicide within a week of discharge than later (i.e. between one week and one year). This was replicated by Pirkola *et al*. (2007) when studying suicide within a year of discharge over two time periods, 1985-1991 and 1995-2001.

1.4.1.3. Employment status

A number of studies investigated the association between employment status and suicide, albeit using different terminology.

Kan, Ho, Dong & Dunn (2007) found that work related stress (work stress, unemployment, job under threat) was an independent predictor of suicide risk. Similarly, Yim *et al*. (2004) found that unemployment was independently associated with suicide after discharge. This was further supported by King *et al*. (2001) who found that loss of job between the time of admission and death (or follow-up for controls) was associated with an OR of 7.88.

In Pirkola *et al*.'s (2007) cohort study, being retired was positively associated with committing suicide within a year after discharge. Similarly, Pirkola *et al*. (2005) found that those committing suicide within a week of discharge were more likely to be retired compared to those committing suicide later.

Hunt *et al*. (2009), McKenzie *et al*. (2001) and Lin *et al*. (2008) found that the employment status of cases and controls was not significantly different.

1.4.1.4. Living situation

Kan *et al*. (2007) found that living alone was an independent risk factor for suicide, associated with an OR of 5.8. However, the confidence interval (CI) was particularly wide denoting a level of imprecision in the findings. King *et al*. (2001) replicated this finding, with an OR of 1.87. It is unclear whether patients were living alone before admission and returned to this situation on discharge, or whether only data referring to living situation on admission was available. In support of the risk of living alone, King *et al*. (2001) reported that admission from shared accommodation was associated with a reduced risk of suicide. This referred to supported group homes and sharing with friends. However, there was a lack of consistency in findings, as there was also evidence that as many cases as controls were living alone (Hunt *et al*., 2009; Hoffman *et al*., 1987), or with family (Yim *et al*., 2004). Furthermore, Hoffman *et al*. (1987) found no differences between cases and controls in terms of living conditions on discharge.

Hunt *et al*. (2009) found that more suicide cases were homeless compared to controls. Although in the regression analysis this factor was associated with an OR of 1.7, it is difficult to interpret because the CI overlapped the null value (0.4-7.0) and the p value was insignificant. Szumilas (2010) argues that it is “inappropriate to interpret an OR with 95% CI that spans the null value as indicating evidence for lack of association” (2010, p. 227). However as this variable was not investigated elsewhere, it is difficult to evaluate whether or not this positive association is ‘true’.

1.4.1.5. Marital status

The majority of studies did not find a relationship between marital status and suicide (Hunt *et al*., 2009; Kan *et al*., 2007; McKenzie *et al*., 2001; Hoffman *et al*., 1987; Tseng *et al*., 2010). However, Pirkola *et al.* (2005) found that being unmarried was positively associated with committing suicide within a week of discharge.

Similarly, Pirkola *et al*. (2007) found that those who committed suicide were more likely to be divorced.

1.4.1.6. Relationship factors

King *et al*. (2001) found that suicide after discharge and the onset of new relationship difficulties was associated with an OR of 4.89. Similarly, Hunt *et al*. (2009) found that adverse life events (most often relationship breakdowns) within three months of the index date were experienced by more suicide cases than controls (OR = 1.9). Pokorny *et al*. (1976) also found that significantly more suicide cases than controls experienced one or more adverse life events post-discharge (p<0.01), based on informants' responses to the Social Readjustment Rating Scale (Holmes, 1967). However, not all adverse events were related to relationships.

1.4.1.7. Summary

Table 1.2 summarises the odds ratios (ORs) (resulting from regression analysis) associated with socio-demographic predictors of suicide.

Not being in work, either through unemployment or retirement was most consistently associated with suicide within a year of discharge, with ORs ranging between 2.04 and 12.2. However, this is based on relatively few studies, therefore should be treated with some caution. Findings in relation to age and gender are mixed. There is some evidence that those who are living alone, single (divorced or unmarried) or have relationship difficulties may be at greater risk of suicide after discharge. However, these findings were not consistent. There were additional challenges in interpreting these results, as it was not clear whether authors were exploring the living situation on admission or at the time of death. Additionally, there was a lack of depth or detail in the data collected, so it was not possible for example to assess the relative social isolation of those living alone. This information may have increased the utility of other findings within this section and added to the literature concerning the link between social support and suicide (Appleby, Dennehy & Thomas, 1999).

Table 1.2 Socio-demographic predictors of suicide within a year of discharge

Variable	Exact variable wording in study	Study	OR/Adjusted OR (95% CI)
Gender	Male	Hunt *et al*. (2009)	2.2 (1.3-3.8)
	Female	Pirkola *et al*. (2005)	2.3 (2.1-2.6)
		Pirkola *et al*. (2007) 1985-1991 1995-2001	 1.78 (1.59-2.00) 1.48 (1.32-1.67)
Employment status	Work related stress	Kan *et al*. (2007)	5.4 (1.5-18.0)
		Yim *et al*. (2004)	12.2 (2.1-70.4)
	Becoming unemployed	King *et al*. (2001)	7.9 (2.1-30.0)
	Retired	Pirkola *et al*. (2007) 1985-1991 1995-2001	 2.04 (1.72-2.41) 2.45 (2.11-2.85)
		Pirkola *et al*. (2005)	2.54 (2.11-3.06)
Living situation	Living alone	Kan *et al*. (2007)	5.8 (1.4-23.0)
		King *et al*. (2001)	1.87 (1.19-2.93)
	Living in shared accommodation at time of admission	King *et al*. (2001)	0.28 (0.10-0.77)
Marital status	Unmarried	Pirkola *et al*. (2005)	1.29 (1.12-1.49)
	Divorced	Pirkola *et al*. (2007) 1985-1991 1995-2001	 1.72 (1.49-1.98) 1.96 (1.72-2.24)
Relationship factors	Recent adverse life events	Hunt *et al*. (2009)	1.9 (1.3-2.8)
	New relationship problems	King *et al*. (2001)	4.89 (1.13-21.15)

1.4.2. Historical predictors of suicide within a year of discharge

1.4.2.1. History of self-harm

An association between history of self-harm and suicide post-discharge was consistently identified in the reviewed studies. Hunt *et al*. (2009) found that history of self-harm was an independent predictor of risk and was associated with the largest OR in the study. Kan *et al*. (2007) and King *et al*. (2001) replicated this finding.

Similarly McKenzie *et al.* (2001) found that a past history of deliberate self-harm (DSH) predicted those committing suicide within three months of discharge (‘early suicide’) versus controls, as well as ‘early suicide’ versus ‘late suicide’ (between three months and the timing of case note review, up to twelve years). A history of DSH was seen in 84% of those committing suicide within three months of discharge compared with 28% of controls.

The method of self-harming behaviour was not reported in the studies reviewed. However, some did report additional context and detail, which provided further insight into the extent of self-harm in post-discharge suicide. Yim *et al*. (2004) and Hoffman *et al*. (1987) described the self-harming behaviour of their sample as ‘suicidal attempts’, suggesting a connection between self-harm and suicidal intent. In this context, Hoffman *et al.* (1987) found that not only had more suicide cases than controls attempted suicide before, but also that their attempts were more frequent and serious. The most serious suicidal attempts defined by Motto (1965) as “an unequivocal attempt to end one’s life” (1965, p. 518) were identified exclusively in the suicide group. Yim *et al.* (2004) found that significantly more suicide cases than controls had attempted suicide in the past (*p*=0.003) and that suicidal attempts were more frequent amongst suicide cases (*p*=0.001). Additionally, Yim *et al*. (2004) reported a significant difference between cases and controls in relation to the violence of the last suicidal attempt (*p*=0.007).

1.4.2.2. History of violence

Hunt *et al*. (2009), Kan *et al*. (2007), Tseng *et al*. (2010) and Yim *et al*. (2004) found no significant differences between cases and controls in terms of a history of violence. The type of violence was not specified in any of these studies.

1.4.2.3 History of substance abuse

King *et al*. (2001) found that misuse of non-prescribed substances was associated with a decreased risk of suicide. However, other case-controlled studies, including Hunt *et al*. (2009), Kan *et al*. (2007) and Yim *et al*. (2004) found no significant differences between cases and controls in terms of a history of substance abuse.

1.4.2.4. Duration of mental illness

There is some evidence in the studies reviewed that duration of mental illness is associated with suicide within a year of discharge. It is unclear how this variable was assessed and measured and so it is difficult to accurately compare study findings. Differences between the assessment and measurement of illness duration between studies may account for the inconsistent findings.

Hunt *et al*. (2009) found that a short illness (diagnosis not specified) of less than twelve months was associated with suicide within three months of discharge, although this was not identified as an independent predictor when the multivariate model was fitted. Tseng *et al*.'s (2010) findings also indicated this association when those who committed suicide within a week or a month of discharge were compared with those committing suicide after a month. However, Kan *et al*. (2007) and Hoffman *et al*. (1987) found no significant differences between cases and controls in relation to this factor (diagnosis not specified).

The utility of these findings is further reduced because the relationship between type of diagnosis and illness duration was not evaluated. Yim *et al*.'s (2004) study was an exception, as the differences between cases and controls, in terms of a lifetime diagnosis of a depressive disorder, were investigated. Although the OR indicated a positive association, the CI overlapped the null value (0.5-3.8) and the differences were insignificant (p=0.59). Therefore interpreting this result is challenging, particularly in the absence of any comparable findings.

1.4.2.5. Previous psychiatric inpatient treatment

Lee *et al*. (2009) found that having had more than three hospitalisations in the year before the index admission was associated with a reduced suicide risk post-discharge (hazard ratio (HR) = 0.379, 95% CI=0.187-0.77). However, no significant findings were reported in any other studies exploring this variable (Hunt *et al*., 2009; Yim *et al.,* 2004; Lin *et al*., 2008).

1.4.2.6. Summary

Table 1.3 provides a summary of the ORs reported in relation to historical predictors of suicide.

Table 1.3 Historical predictors of suicide within a year of discharge

Variable	Exact variable wording in study	Study	OR/ Adjusted OR (95% CI)
History of self-harm	Previous/history of DSH	Hunt *et al*. (2009)	3.2 (1.9-5.5)
		King *et al.* (2001)	4.09 (2.58-6.48)
		Kan *et al*. (2007)	2.3 (1.0-5.0)
		McKenzie *et al*. (2001) Early suicides vs. controls Early vs. late suicides	 13.8 (3.6-52.6) 5.1 (1.3-19.9)
	Past suicidal attempt	Yim *et al*. (2004)	3.4 (1.2-9.6)
	Mean no. of suicidal attempts	Yim *et al*. (2004)	2.0 (1.3-3.1)
	Violent method of self-harm in the last suicidal attempt	Yim *et al.* (2004)	4.5 (1.5-13.3)
History of substance abuse	Misuse of non-prescribed substances	King *et al*. (2001)	0.39 (0.17-0.88)
Duration of illness	Duration of illness less than twelve months	Hunt *et al.* (2009)	1.6 (1.0-2.6)
	Duration of illness more than twelve months	Tseng et al. (2010) Suicide in one week vs. later Suicide in one month vs. later	0.574 (0.353-0.934) 0.576 (0.397-0.835)
	Lifetime diagnosis of a depressive disorder	Yim *et al*. (2004)	1.3. (0.5-3.8)

The association between suicide and history of self-harm was a well-replicated finding, with ORs ranging from 2.3 to 13.8. This is reflected in risk factors for suicide in general (Flood & Seager 1968; Hawton & Fagg, 1988; Robin, Brook & Freeman-Browne, 1968; Roy, 1982), but interestingly, McKenzie *et al.*'s (2001) findings indicate that the association between DSH and suicide is stronger in the first three months of discharge compared to later. However, this particular comparison was not conducted within any other studies; therefore, as yet, it has not been replicated.

The findings indicate that substance abuse is not significantly associated with suicide within a year of discharge. This is surprising given that substance misuse is a major risk factor for suicide in the general population (Murphy, 2000) and amongst those with mental illness (e.g. Buhler, Hambrecht, Loffler, an der Heiden & Hafner, 2002). In the absence of further information about the type of substance abuse being explored or clarity about the methods of assessment or measurement, it is difficult to understand this discrepancy.

Findings in relation to duration of illness were inconsistent and not specific to any particular diagnosis. In general the number of previous psychiatric admissions has not been found to be significantly different between cases and controls. Although Lee *et al*. (2009) found this variable to be significant, this sample differed from other studies as it was limited to those with a diagnosis of schizophrenia.

1.4.3. Clinical predictors of suicide within a year of discharge

1.4.3.1. Diagnosis and symptomology

All of the studies reviewed, with the exception of Hoffman *et al.* (1987) found significant differences between suicide cases and controls in terms of diagnosis.

In studies investigating suicide within three months of discharge, diagnosis of affective disorder was positively associated with suicide (Hunt *et al*., 2009; McKenzie *et al.*, 2001). Pirkola *et al*. (2005) also reported that those committing suicide were more likely to have been given a discharge diagnosis of affective disorder. However this study identified an additional relationship between suicide and schizophrenia and similar psychoses, in those committing suicide within a week of discharge.

Similarly, Tseng *et al*. (2010) found a positive association between suicide and three different diagnoses (schizophrenia, depression, neurotic spectrum), though a diagnosis of schizophrenia was the only predictor reaching statistical significance. However the other diagnostic groups contained small numbers, therefore there may have been insufficient power to detect a true association.

Yim *et al*. (2004) and King *et al*. (2001) investigated symptomatology. Yim *et al*. (2004) found that significantly more cases than controls had expressed depressive symptoms prior to admission (p=0.03), but the difference between cases and controls in terms of depressive symptoms communicated during the last community visit did not reach significance. King *et al*. (2001) found that those who committed suicide were more likely to present as ‘hopeless’ than surviving controls.

Two of the studies reviewed considered psychiatric co-morbidity. Hunt *et al.* (2009) found this to be an independent predictor of risk, but this was not replicated by Yim *et al*. (2004).

There are a number of factors complicating the interpretation of these findings. The method used to diagnose patients is unclear, (some but not all cite the use of the ICD) which raises doubts about the consistency of the diagnoses across time and place. Additionally, there are broader issues in relation to the low inter-rater reliability of diagnoses (Bentall, 2004; Aboraya, 2007; Freedman *et al*., 2013). Finally, whilst an association between post-discharge suicide and a diagnosis of affective disorder has been identified, the specific diagnosis within this large categorisation has not been specified.

1.4.3.2. Suicidal behaviour

Some of the reviewed studies reported on suicidal behaviour either preceding the index hospital admission or during the index admission, though the timing was not always clearly stated.

Kan *et al*. (2007) found that being admitted due to DSH/suicidal ideation was an independent predictor of suicide risk. King *et al*. (2001) and Yim *et al*. (2004) replicated this finding, though it was not specifically stated that this was the reason for the index admission. Hoffman *et al*. (1987) found that more patients in the suicide group presented with suicidal behaviour before the index admission ($p<0.01$) and more had been referred to hospital because of ‘self-endangering’ behaviour ($p<0.01$).

Hoffman *et al*. (1987) found no differences between cases and controls in terms of suicidal behaviour during the index hospital stay (p value not reported). McKenzie *et al*. (2001) found that a suicidal attempt or communication of suicidal intent during the last hospital admission was associated with an OR of 10.5. The OR reduced to 1.9 (95% CI=0.5-7.3) when comparing ‘early’ (within three months) and ‘late’ suicides (between three months and one year). Hunt *et al*. (2009) found that suicidal ideation was an independent predictor of risk, although it was unclear whether this referred to suicidal ideation before, during admission or post-discharge.

1.4.3.3. Physical illness

Tseng *et al*. (2010) found that comorbidity of cancer was positively associated with committing suicide within one month of discharge. Other studies found that as many cases as controls suffered from a physical illness, although the type of illness was not specified (Yim *et al*., 2004; McKenzie *et al*., 2001). Hoffman *et al*. (1987) found no significant difference between cases and controls in terms of ‘severe chronic disability’ (p value not reported).

1.4.3.4. Summary

Table 1.4 provides a summary of the ORs reported in relation to clinical predictors of suicide.

Table 1.4 Clinical predictors of suicide within a year of discharge

Variable	**Exact variable wording in study**	**Study**	**OR/ Adjusted OR (95% CI)**
Diagnosis	Affective/mood disorder	Hunt *et al.* (2009)	2.3 (1.3-3.9)
		McKenzie *et al.* (2001) Early suicides vs. controls	4.7 (1.5-14.5)
		Pirkola *et al.* (2005)	2.3 (1.68-3.08)
	Schizophrenia and similar psychoses	Pirkola *et al.* (2005)	2.3 (1.67-3.07)
		Tseng *et al.* (2010)	1.585 (1.005-2.500)
	Any secondary psychiatric diagnosis	Hunt *et al.* (2009)	1.8 (1.0-3.3)
Symptomology	Depressive symptoms prior to admission	Yim *et al.* (2004)	5.5 (1.2-24.8)
	Evidence of hopelessness	King *et al.* (2001)	1.82 (1.04-3.19)
	Evidence of delusions at index admission	King *et al.* (2001)	0.48 (0.26-0.86)
Suicidal behaviour	Symptoms of suicidal ideation	Hunt *et al.* (2009)	2.5 (1.0-5.9)
	Suicidal ideation/attempt before index admission	Yim *et al.* (2004)	3.4 (1.5-8.0)
	Admitted for DSH/suicidal ideation	Kan *et al.* (2007)	3.2 (1.3-7.8)
	Suicidal ideas during index admission	King *et al.* (2001)	1.93 (1.22-3.06)
	Suicidal attempt/intent during index admission	McKenzie *et al.* (2001) Early suicides vs. controls	10.5 (1.7-63.2)
Physical illness	Comorbidity with cancer	Tseng *et al.* (2010)	2.508 (1.186-5.302)

Affective disorders, schizophrenia, anxiety and personality disorders (type not specified) have all been found to be associated with suicide post-discharge. Of these diagnoses, the most consistent association is between affective disorders and suicide, particularly in the first three months of discharge, with ORs ranging from 2.3-4.7. However, for the reasons previously discussed, drawing conclusions on the basis of these findings is challenging.

Suicidal ideation or suicidal attempts directly before or during the index admission were found to be associated with suicide within a year of discharge. However, it is difficult to determine how suicidal behaviour was determined or assessed, therefore the reliability of the findings is questionable and their utility is reduced.

Comorbidity of cancer was found to be associated with suicide risk, but was only investigated in one paper. However, it is supported by studies investigating risk factors for suicide in general (Anguiano, Mayer, Piven & Rosenstein, 2012).

1.4.4. Service organisation and delivery predictors of suicide within a year of discharge

1.4.4.1. Admission status

Four of the studies reviewed analysed data in relation to patients' admission status. Two studies were located in Hong Kong (Yim *et al*., 2004: Kan *et al*., 2007) and two in the UK (McKenzie *et al*., 2001; Hunt *et al*., 2009).

Findings within and across cultures were mixed. Yim *et al.* (2004) found that as many cases as controls were admitted under a compulsory admission. In contrast, Kan *et al*. (2007) found that being under a compulsory admission was associated with an OR of 3.1. Although McKenzie *et al.* (2001) found that more suicide cases than controls had been detained under the Mental Health Act (MHA) (OR=2.3, 95% CI=0.5-9.8), this difference did not reach statistical significance.

In contrast, Hunt *et al*. (2009) found that those who had committed suicide were less likely than controls to have been detained under the MHA (OR=0.6). Hunt *et al*. (2009) used this to suggest that being detained may be a protective factor for suicide, as these patients may be risk managed more closely (though this hypothesis has not been supported by other studies).

Findings in relation to admission status lack external validity and reliability, due to vast cultural differences in mental health policy and practice. For example, Hong Kong lacks a specific mental health policy (Cheung, Lam & Hung, 2011) and Yim *et al*. (2004) state that in Hong Kong an illness has to be quite severe to warrant admission. This indicates that admission criterion, thresholds, pathways and statuses are likely to hold different meanings across cultures.

1.4.4.2. Length of stay

While Lee *et al*. (2009) found that both short and long hospital stays increased suicide risk, six studies found that length of stay was not a risk factor for post-discharge suicide (Lin *et al*., 2008; McKenzie *et al*., 2001; Tseng *et al.,* 2010; Hunt *et al.*, 2009; Hoffman *et al.,* 1987; Yim *et al*., 2004).

1.4.4.3. Psychopharmacology

Four studies reported on the pharmacological treatment patients were receiving either during their admission, on discharge, or at the time of death. The association between suicide and other forms of treatment were not investigated, limiting a broader understanding of patients' inpatient treatment or care. Modestin *et al*. (2002) was the exception, reporting on the number of cases and controls 'in therapy', however, the details of this were not stated.

Kan *et al*. (2007) found that from the time of admission to the time of suicide (or the equivalent date for controls), significantly more cases than controls were taking antidepressants, in line with previous findings in relation to diagnosis (section 1.4.3.1). Yim *et al.* (2004) and Hoffman *et al.* (1987) also found that significantly more suicides than controls were prescribed antidepressants on discharge. In contrast, Modestin *et al*. (2002) reported that significantly more *controls* than cases were receiving psychotrophic medication at the time of death (or equivalent for controls) (*p*=<0.01). Yim *et al.* (2004) found that as many cases as controls were prescribed a mood stabiliser.

Two studies reported on the association between suicide and drug compliance, although it was unclear how this was measured. Yim *et al*. (2004) found that significantly more cases than controls were reported as being poorly compliant with drug treatment. In contrast, Hunt *et al*. (2009) found that suicide was not associated with non-compliance.

1.4.4.4. Discharge circumstances

Seven studies reported on the circumstances surrounding patients' discharge, with over half based on a non-UK population. The studies offered limited explanation of the discharge guidelines or processes in operation in the study locations. To put this in context, within the UK at least, there does not seem to be a minimum set of standards, despite a number of guidelines for discharge planning (e.g. CSIP, 2007; DoH, 2010; DoH, 2004). It is more common for individual NHS Trusts and wards to develop their own discharge policies (Simons, Petch & Caplan, 2002). Therefore there are likely to be inconsistencies in discharge planning within the UK studies and inevitably across cultures, impacting on the comparability of findings relating to this variable.

With these concerns in mind, Hunt *et al*. (2009) found that patient-initiated discharge was an independent predictor of suicide (OR=2.0, 95% CI=1.3-3.1). Similarly, Lin *et al*. (2008) found that those who initiated their own discharge were more likely to commit suicide (HR = 2.85, 95% CI=1.387-5.856). King *et al*. (2001) found that 'not planned discharge' was an independent risk factor for suicide within a year of discharge (OR=2.73). Lee *et al*. (2008) also found significant differences between cases and controls in terms of unplanned discharge (*p*=0.016). However, this was not a significant factor when confounding factors were adjusted for in the regression analysis.

Yim *et al*. (2004) reported that 'discharge against medical advice' was a significant factor in the univariate analysis (*p*=0.08), although it became insignificant when entered into the final regression model. Kan *et al*. (2007) and McKenzie *et al*. (2001) found that discharge against medical advice was not a risk factor for suicide within a year after discharge.

1.4.4.5. Contact with services after discharge

A number of factors explored within studies were broadly based on gaining an understanding of patients' contact with services after discharge.

King *et al*. (2001) assessed continuity of care by studying the number of days a patient had been 'out of contact', (interval between the date of a missed appointment, or self-discharge, and the date of next contact), reporting that continuous care was associated with a decreased risk of suicide. This result is supported by Kan *et al*. (2007) who found that being 'out of contact at follow-up' was associated with an OR of 7.9. Similarly, Hunt *et al*. (2009) found that a patient missing their last appointment with psychiatric services was an independent predictor of suicide.

The findings in relation to continuity of care are somewhat contradictory, as in addition to suicide cases being more likely to miss appointments, there is also evidence that they are more likely to seek help or engage with services prior to death. Hunt *et al*. (2009) found that those who committed suicide were more likely to have met with a member of the mental health team within a week prior to their death (OR=2.2). At last contact, those reporting depressive symptoms, hopelessness and suicidal ideas were all more likely to die by suicide. Similarly, Yim *et al*. (2004) found that suicide cases were more likely to have had contact with a psychiatrist or attended emergency departments in the week preceding death than controls (OR=2.0 and 4.0 respectively).

King *et al.* (2001) investigated the impact of changes in personnel after discharge on post-discharge suicide and found that a key professional being on leave or leaving around the time of discharge was associated with an OR of 16.82. Although this is a particularly high OR, no other studies investigated this variable so it is difficult to determine reliability. Furthermore, this strong association may have been biased by the retrospective nature of the study which relied on clinicians providing information with hindsight.

1.4.4.6. Summary

Table 1.5 provides a summary of the ORs reported in relation to service organisation and delivery predictors of suicide.

Table 1.5 Service organisation and delivery predictors of suicide within a year of discharge

Variable	Exact variable wording in study	Study	OR/ Adjusted OR (95% CI)
Admission status	Compulsory admission	Kan *et al*. (2007)	3.1 (1.1-8.7)
	Detained under the MHA	Hunt *et al*. (2009)	0.6 (0.4-1.0)
Inpatient psychopharmacology	Antidepressants	Yim *et al*. (2004)	2.3 (0.9-5.6)
	Poor drug compliance	Yim *et al*. (2004)	8.0 (1.8-34.8)
Discharge circumstances	Discharge against medical advice	Yim *et al*. (2004)	4.0 (0.8-18.8)
	Not planned discharge	King *et al*. (2001)	2.73 (1.77-4.22)
Contact with services after discharge	Contact with health care services in last week before death	Yim *et al*. (2004)	4.0 (1.3-11.9)
		Hunt *et al*. (2009)	2.2 (1.3-3.8)
	Contact with A&E departments in the last week	Yim *et al*. (2004)	4.0 (0.8-18.8)
	Out of contact at follow-up	Kan *et al*. (2007)	7.9 (1.8-33)
	Missed last appointment	Hunt *et al*. (2009)	2.3 (1.4-3.8)
	Continuous care	King *et al*. (2001)	0.63 (0.40-1.00)
	Key personnel on leave or having left	King *et al*. (2001)	16.82 (3.54-79.80)

There are significant issues interpreting the findings in relation to service organisation and delivery factors due to marked cultural differences between mental health systems and inpatient care. However, there is evidence both within the UK and across different cultures that unplanned discharge and breaks in follow-up care are associated with increased suicide risk. This is alongside findings that suicide cases are more likely than controls to have had contact with mental health service staff shortly before death (or the index date), reflecting the difficulty predicting suicide in psychiatric patients (Hughes, 1995).

Findings of the reviewed studies were inconsistent in relation to length of hospital stay or admission status. In relation to admission status, level of risk may have been a confounding variable. However, this could not be accounted for as this information was not part of the dataset.

There was an exclusive focus on pharmacological treatment, thereby reducing the opportunity to gain a more holistic understanding of the relationship between inpatient care and suicide. Key factors not explored include wider biopsychosocial interventions (e.g. occupational therapy, physiotherapy input, art therapy, and psycho-education) and therapeutic relationships with staff and fellow inpatients.

1.5. Discussion

The primary aim of this review was to critically evaluate research investigating predictors of suicide up to a year after discharge from psychiatric inpatient care. The four categories of predictors reflected the multi-factorial aetiology of suicide and the importance of adopting a broad theoretical perspective in understanding the phenomenon (Beautrais, Collings & Ehrhardt, 2005).

1.5.1. Summary of findings

There were marked inconsistencies in the findings of the reviewed studies. This is likely to be due to a number of methodological differences, alongside cultural and systemic variations between the researched populations (WHO, 2001). The inconsistencies also reflect the difficulty predicting suicide in general and the individual differences between those who commit suicide (Powell, Geddes, Deeks, Goldacre & Hawton, 2000).

However, this review has identified factors positively associated with post-discharge suicide both within the UK and across other cultures. These indicate that those who commit suicide within a year of discharge are more likely to have:

- a history of self-harm;
- been admitted following suicidal behaviour;
- a diagnosis of affective disorder;
- expressed depressive symptomatology either during admission or on follow-up;
- experienced a recent relationship breakdown;
- had a break in follow-up care after discharge;
- experienced a change in the community healthcare staff supporting them (only identified in one UK study, but associated with a particularly high OR); and/or
- initiated their own discharge.

Few studies (Hunt *et al.,* 2009, King *et al*., 2001; Tseng *et al*., 2010) considered predictors of reduced risk of suicide post-discharge. However, continuous care appears to be the most robust factor (King *et al*., 2001).

Suicide risk is often described as a complex interaction between multiple factors (e.g. McLean, Maxwell, Platt, Harris & Jepson, 2008). Although only two studies investigated the prevalence of multiple risk factors, both reported that this was higher among suicide cases than controls (Hunt *et al*., 2009; King *et al*., 2001).

1.5.2. Summary of the critical appraisal of reviewed studies

The findings outlined above should be interpreted with caution due to the shortcomings of the included studies. One of the most significant shortcomings was that there was little information about how variables were measured or assessed, limiting the depth of understanding and the comparability of studies. Additionally, there was an over-reliance on the reliability and consistency of clinicians when assessing patients and recording data, and some clinical data was missing. Further concerns relate to the possibility of missed or misidentification of suicide cases. Despite these threats to study quality, 69% of the studies were assessed as meeting over 50% of the quality criteria.

1.5.3. Discussion of findings

These findings are broadly in line with previous reviews (Troister *et al*., 2008; Large *et al*., 2011) and many reflect risk factors for suicide in general. For example, prior history of suicidal behaviour has been identified as one of the most reliable and potent predictors of future suicide (Christiansen & Jensen, 2007; Haw, Bergen, Casey & Hawton, 2007; Zonda, 2006). Affective disorder including major depressive disorder and bipolar disorder are also associated with particularly elevated rates of suicide in general (Bostwick & Pankratz, 2000; Harris & Barraclough, 1997). Indices of family conflict have been found to be robust risk factors (e.g. Bastia & Kar, 2009) and numerous studies have demonstrated an association between unemployment and suicide (e.g. Brown, Beck, Steer & Grisham, 2000). However, the occurrence of these factors during the post-discharge period may be especially significant due to the vulnerability of being in transition from hospital to community care (Manuel, Hinterland, Conover & Herman, 2012).

Although some of the predictors of suicide identified in this review are similar to risk factors in the general population, this review has highlighted some factors which may help to understand the particularly high rate of suicide in the post-discharge period. The findings indicate that reduced continuity of care is implicated in suicide post-discharge. This supports Meehan *et al*.'s (2006) proposal that suicide prevention may be more likely if intensive care is maintained and withdrawn only gradually following discharge. Discharge from hospital is characterised by significant changes in the level and intensity of support (Gerson & Rose 2012), and the loss of personal relationships with staff and other patients (Manuel *et al*., 2012). Therefore discharge could be experienced by some as abandonment, thereby increasing suicide risk (Ledgerwood, 1999). This suggestion would indicate that continuity of care may be a crucial mechanism for 'holding' a patient.

Interestingly, the findings from this review indicate that although more men than women commit suicide in the general population (ONS, 2013), this gender difference does not seem to be reflected in post-discharge suicide.

1.5.4. Limitations

The literature was reviewed systematically to gain a broad, up to date understanding of the predictors of suicide within a year post-discharge, with a particular focus on the applicability of findings to the UK. However, there were several limitations. Firstly, only articles published in English language journals were included. Therefore it is possible that some key studies were omitted. Secondly, although the quality assessment tool was reviewed externally, the findings of the current review were not corroborated by a second researcher. Thirdly, only those variables reported within three or more studies were included, due to the wealth of data to review. Additionally, this ensured that only the most frequently studied variables were synthesised, therefore increasing the reliability of the conclusions drawn from the reviewed studies. Finally, a number of studies included in this review were located outside the UK, potentially limiting the utility and relevance of the findings. However, the most robust associations with suicide after discharge were identified in studies both within and outside the UK, highlighting the "universal relevance" (Hunt *et al*., 2009, p. 448) of certain suicide predictors.

1.5.5 Implications

1.5.5.1. Research implications

This review has highlighted that although there is a growing literature surrounding post-discharge suicide, there are a number of gaps. Further areas for investigation include:

- Patients' experience of inpatient care
- Patients' social support and social networks
- A broader exploration of the 'treatment' patients receive during an inpatient admission
- A focus on the early post-discharge period, as this is the time of greatest risk (DoH, 2001; Qin and Nordencroft, 2005)

- Protective factors that might mediate against suicide in the early post-discharge period
- A consideration of the interplay between different predictors of risk
- Developing a theoretical understanding of suicide in the post-discharge period
- Evaluating interventions aimed at supporting patients during the discharge period

There are inherent difficulties researching this area because ultimately no study design or methodology will be able to capture the individual state of mind of those who commit suicide. Therefore research either relies on exploring relationships between sets of data, or on collecting data from third party sources or those who have attempted suicide, all of which have clear limitations. However, it remains crucial to expand this research area to gain a more thorough knowledge and understanding of the risk factors, in order to inform and target suicide prevention strategies and ultimately reduce suicide rates.

1.5.5.2. Clinical implications

The purpose of conducting this review was to synthesise the predictors of suicide in the post-discharge period to inform the clinical management of those who are discharged from mental health inpatient care. Although this review has identified some well-replicated suicide predictors, the strength of the association is not sufficient to enable accurate prediction of suicide. Patients may possess the identified risk factors, but a large proportion will not go on to commit suicide.

Equally, a proportion of those deemed to be at low risk, will commit suicide (Large *et al*., 2011; Crawford, 2004).

Therefore the clinical utility of this review is not in being able to identify patients at greatest risk of suicide, but in demonstrating the importance of enhanced support and follow-up upon discharge in efforts to reduce post-discharge suicide. As such, the implications of this review relate to:

- discharge planning; and
- continuity of care.

The findings from this review indicate that those who commit suicide post-discharge are more likely to have had breaks in follow-up care. The association between reduced continuity of care and suicide, also reported elsewhere (e.g. Sheppard, 1996; Hulten & Wasserman, 1998) emphasises the importance of thorough, thoughtful and considered discharge planning (Crawford, de Jonge, Freeman & Weaver, 2004). This reported interplay indicates that interventions in place to adequately prepare patients for discharge are more likely to result in continuity of care. Crawford (2004) proposed a number of interventions aimed at improving discharge preparation for mental health services and patients. These interventions include facilitating discharge preparation groups, meeting community staff before discharge, and patients having support from service users as ‘experts by experience’ during the discharge period. Crawford (2004) also highlighted the importance of discharge coordinators in facilitating communication and liaising with patients and carers.

Another particularly relevant finding from this review was the association between post-discharge suicide and patient-initiated discharge. In working to avoid self-initiated discharge, mental health staff should make every effort to work collaboratively with patients to develop discharge plans which are understood by, and acceptable to, everyone involved. Additionally, creating an effective working alliance is likely to help patients feel able to share their thoughts, feelings and concerns with staff before deciding to discharge themselves. If a premature discharge does occur, given the importance of continuity of care, it is crucial that staff work assertively to re-engage patients in the community. Luxton, June and Comtois' (2013) literature review provides support for assertively engaging those at high risk. They concluded that repeated post-discharge follow-up contacts, in the form of telephone calls or postal communication, appear to reduce suicide risk.

The findings from this review support national recommendations for service provision in the post-discharge period. The National Suicide Prevention Strategy (DoH, 2002) states that those with severe mental illness or a recent history of self-harm should be followed up in the community within seven days. Further recommendations have been made to follow-up those considered at high risk of suicide within 48 hours of discharge (National Institute of Mental Health (NIMHE), 2003). In the studies reviewed, between 2.8% (Hunt *et al*., 2009) and 16% (Lee *et al*., 2009) of cases committed suicide the day after discharge. Therefore there could be an argument for further reducing the time between discharge and follow-up.

In conclusion, the findings from this review indicate that enhancing the support and follow-up of patients around the time of discharge, is likely to be particularly beneficial in the drive to reduce suicide rates during the high-risk period after discharge from inpatient care.

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Chapter Two: Empirical Paper

Negotiating transition: An exploratory study of female family carers' experiences of the discharge process from acute inpatient mental health services

In preparation for submission to *Issues in Mental Health Nursing* (see Appendix G for Author instructions)

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2.1. Abstract

Objective: There is a heavy reliance on family members to care for their relatives after they have been discharged from inpatient mental health services. However, carers' experiences of this transitional period are not well understood. This study aims to explore family members' lived experiences of the discharge process from inpatient mental health services.

Method: Semi-structured interviews were conducted with six family members and the resulting transcripts were analysed using Interpretative Phenomenological Analysis (IPA).

Results: Three phenomenological themes emerged from the data: *'Being out of the loop', 'Getting back on track'* and *'It's all down to me'.* Carers felt disregarded, excluded and undervalued by mental health staff. They received little or no warning about the point of discharge and so felt unprepared and anxious. Despite this, carers worked to regain structure and routine and re-connect with their relatives. However, carers experienced the task upon discharge as all-consuming and exhausting and were 'kept afloat' by the personal support they received.

Conclusions: Carers' accounts highlighted a significant discrepancy between policy and practice in relation to the involvement of carers in the discharge process. The clinical recommendations consider how services can strengthen the position of carers in the discharge process to increase the likelihood of a successful transition.

Key words: *Carers' experiences, discharge, hospitalisation, transition, Interpretative Phenomenological Analysis*

2.2. Introduction

There are an estimated 6.4 million relatives, partners and friends providing unpaid care in the UK, saving the government an estimated £119 billion a year (Carers UK, 2011). One in four are caring for someone with a mental illness (National Mental Health Development Unit (NMHDU), 2010), but they have been described as a "hidden, vulnerable, ostracised, largely invisible workforce" (Gray, Robinson, Seddon & Roberts, 2010, p. 476). The stress, distress and burden of caring for someone with a mental illness is a well-replicated finding (e.g. Saunders, 2003; Awad & Voruganti, 2008; Fortune, Smith & Garvey, 2005). Psychiatric hospital admissions are understood to be especially stressful, distressing and traumatic periods for carers (Wynaden & Orb, 2005). However, very little is known about carers' experiences of the discharge process and the transition to community living, despite their crucial role in supporting this adjustment period for those they care for (Chernomas, Clarke & Marchinko, 2008).

2.2.1. The changing role of psychiatric inpatient care and its impact on carers

The implementation of the National Health Service (NHS) and Community Care Act (1990) resulted in those with mental illness being cared for in the community, rather than institutionalised psychiatric hospitals. This extensive transformation has led to a reduction in the number of psychiatric hospital beds, with greater emphasis on crisis management admissions, resulting in shorter inpatient stays (Wilkinson & McAndrew, 2008). Consequently, patients are likely to be discharged experiencing residual symptoms that adversely affect their abilities to adjust to the demands of community living (Gerson & Rose, 2012). Therefore, there is an increased reliance on family and friends to provide the necessary support with input from community psychiatric services (Jubb & Shanley, 2002). It has been argued that these changes to mental health services have resulted in a devolution of responsibility to carers (Parker & Clarke, 2002) and an expectation that family and friends will adopt the carer role previously provided by health care professionals within inpatient settings (Lloyd & Carson, 2005).

2.2.2. Involving carers in the hospital discharge process

Coupled with community care, user and carer involvement has become a central component of mental health policy (e.g. Department of Health (DoH), 1999; National Institute of Mental Health (NIMH), 2004). One of the key outcomes of the 2008 government's carers strategy (DoH, 2008) was that by 2018, "carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role" (2008, p. 9).

An updated carers outcome strategy (DoH, 2010) highlights the importance of involving carers in "planning and designing hospital discharge arrangements…as they are key partners in ensuring effective delivery of care at home" (2010, p. 10). A number of documents discuss good practice for mental health professionals working with carers during the hospital discharge process (e.g. Association of Directors of Adult Social Services (ADASS), 2010; DoH, 2010; NMHDU, 2010). Taken together these documents demonstrate a clear recognition of the importance of identifying, assessing and supporting carers as "expert partners in hospital discharge" (ADASS, 2010, p. 4).

2.2.3. Carers’ experiences of the discharge process

Despite the array of national policies and good practice documents, a UK scoping review investigating the involvement of carers during discharge, highlighted that a gap remains between policy and practice (Borthwick, Newbronner & Stuttard, 2009). However, this review was predominantly based on the findings of research undertaken by County Councils and voluntary organisations, which was lacking in depth and methodological rigour. Examples of qualitative research with enhanced rigour, depth and focus is evident within the physical health/neurological literature exploring carers’ experiences. In Plank, Mazzoni & Cavada’s (2012) study exploring carers’ experiences during the transition from a rehabilitation unit to home, a recurring theme voiced by carers was ‘being responsible for everything.’

No studies within mental health literature were identified that endeavoured to specifically and directly explore carers’ experiences of the discharge process from inpatient mental health services and the transition to community living. However, the two studies below utilised qualitative methodologies to explore family members’ experience of psychiatric hospitalisation and in doing so referred to experiences of discharge.

Clarke and Winsor (2010) interviewed ten parents following their child’s first psychiatric hospitalisation. One of the emerging themes was ‘feeling excluded during the discharge’. Parents had been invited to discharge meetings but felt intimidated, with their questions going unanswered. They reported being given little warning of the discharge and having insufficient time to adjust to the idea of discharge or prepare to care for their child at home.

Hickman (2011), using IPA principles, explored the experiential impact of hospitalisation as understood by the families of young people under the care of Early Intervention Services for first-episode psychosis. The author reported that parents felt ‘unprepared’ for discharge, ‘out of control’ and inadequately supported following their relative’s discharge.

Although exploring experiences of hospital discharge was not the primary aim of these studies, it is evident that this was a significant and meaningful experience, warranting a more focused and in-depth exploration.

2.2.4. Rationale

For those with mental illness, the period following inpatient treatment is a time of increased risk of stress (Gerson & Rose, 2012), violence against others (Steadman *et al*., 1998) and suicide (Appleby, Dennehy & Thomas, 1999). Given the significance of carers in supporting this adjustment (Cherromas *et al*., 2008) and the heavy reliance on them, it is important to understand carers’ experiences and perceptions of their needs during this period to maximise their positive impact.

There is currently no published research that specifically explores the experiences of the discharge process for those caring for someone with a mental illness. Given this, the current research aims to begin to address this gap by developing an understanding of carers’ experiences of the discharge process, and how they negotiate the transition from hospital to community living. The current research will also provide an opportunity to consider ways in which carers’ experiences of discharge could be improved.

2.2.5. Aims and research questions

This research intends to extend the current literature base by concentrating more specifically on carers' experiences of the discharge process. The following questions were developed to aid the central aims:

- What sense do family members make of their role during the discharge and transition process?
- What factors do family members perceive as important in making a positive or negative difference to their experience of discharge and transition?

2.3. Method

2.3.1. Participants

The population of interest was those caring for a family member who had been admitted to an inpatient mental health unit in the previous two years. Previous studies were referred to in defining this time period (Wilkinson & McAndrew, 2008). The sample was restricted to female family members in order to increase homogeneity (in line with the chosen analytical method, Interpretative Phenomenological Analysis, IPA, Smith, 1995), as it has been found that caring is experienced differently by men and women (McWilliams, Hill, Mannion, Kinsella & O'Callaghan, 2007; Moller, Gudde, Folden & Linaker, 2009). Women were selected as there are more female than male carers (NHS Information centre for Health and Social Care, 2010). For clarity, the inclusion and exclusion criteria are listed in table 2.1.

Table 2.1 Participant inclusion and exclusion criteria

Inclusion criteria	Female family members (partners, siblings, parents, children) who at the time of their relatives' most recent hospitalisation were: 1) either living with or visiting/meeting their family member at least three times a week; and 2) engaged in providing care or support for their family member (N.B. caring definition in line with Jankovic *et al.*, 2011).
	Female family members caring for a relative who was admitted to an acute inpatient mental health service within the last two years.
	Female family members who were able to talk about their experiences.
Exclusion criteria	Female family members, who the researcher felt, based on ethical and clinical judgement, to be unable to provide informed consent to participate in the study.

Six participants were recruited; three mothers, one wife, one daughter and one sister. This is in line with advice from Smith, Flowers & Larkin (2009), who argue that four to ten participant interviews allows for an appropriate level of analysis. Table 2.2 provides a summary of the participants.

Table 2.2 Participant summary information

Pseudonym	Age	Person cared for (diagnosis as described by carer)	Carer circumstances
Brenda	63	Son (schizophrenia)	Retired, married, lives with her son and husband, also has a daughter who lives elsewhere, has been a carer for the past ten years.
Dianne	72	Daughter (depression, manic psychosis, substance abuse)	Retired, widow, lives with her daughter, also has a son who lives elsewhere, has been caring sporadically for four years and more intensively in the last year.
Elaine	48	Sister (schizophrenia, multiple personality disorder, bipolar disorder)	Unemployed, divorced, lives alone, daughter lives close by, full time carer for her mother who has Alzheimer's, has been caring sporadically for her sister over the past fifteen to twenty years.
Helen	60	Husband (depression, recent hypomanic episode)	Employed full time, lives with husband, has two adult children who live elsewhere, has been a carer for past four-five years.
Margaret	68	Daughter (bipolar disorder, personality disorder)	Retired, divorced, has a partner, lives alone, daughter lives close by, no other children, has been a carer for the past twenty-eight years.
Stephanie	25	Mother (bipolar disorder)	Unemployed, single, lives with mother and older brother, father is ill and is cared for in a nursing home, provided intermittent care for many years but more intensive care in the last year.

2.3.1.1. Recruitment

Participants were recruited through two carer support services in the West Midlands. Potential participants were identified by carer support workers using a purposive sampling approach.

Recruiting through charities specifically designed to support carers was a demonstration of the commitment within this study to give a voice to individual carers as experts on their experiences (thus maintaining the idiographic underpinnings of IPA). As this study was focused on a period of service transition, carers' charities were particularly appropriate due to their presence in both hospital and community settings. This method of recruitment has been successful in previous studies (e.g. Wilkinson & McAndrew, 2008).

Twenty one 'invitation packs' were sent to carers by the carer support workers. This included a covering letter written from them (see Appendix L & M), a letter from the lead researcher with a reply slip to express interest in participating (see Appendix N) and a participant information sheet (see Appendix O). Ten of these were returned and following a phone call with the responders, six met the study criteria. A further two potential participants were later identified, however as they were experiencing significant distress at the time, it was felt ethically unsound to approach them.

2.3.2. Design and materials

2.3.2.1. Design

Due to the exploratory and descriptive nature of the research question, a qualitative approach was adopted. IPA (e.g. Smith, 1996; Smith & Osborn, 2008) was chosen to guide data collection and analysis. The value of IPA is well-established and it is one of the most frequently used qualitative methods in clinical psychology (Smith, 2011). A number of papers provide evidence that IPA has the potential to contribute richness and depth to our understanding of carers' experiences (e.g. McCann, Lubman & Clark, 2011; Penny, Newton & Larkin, 2009). The idiographic approach of IPA is consistent with the research aims; to report in detail about how a particular phenomenon has been understood by particular people, in a particular context, rather than making claims about larger groups (Smith *et al*., 2009). IPA was particularly appealing as it asserts to give voice to participants and therefore could be especially empowering in this context, as carers are described as hidden and undervalued (e.g. Gray *et al.,* 2010). Additionally, IPA is particularly appropriate when dealing with new or under researched areas and when the researcher seeks to understand process and change (Smith, 2004).

2.3.2.2. Materials

In IPA research, a semi-structured interview format is considered to be the most appropriate form of data collection (Smith *et al*., 2009). To facilitate this, an interview schedule was developed by the researcher, in collaboration with research supervisors and carers attending a support group (see Appendix Q). The schedule was designed to be consistent with the epistemological underpinnings of an IPA approach. The questions were open-ended to enable the participants to navigate the conversation to areas holding the greatest meaning to them.

The interview schedule focused on eliciting participants' narratives about their experiences of the process of discharge and transition from hospital to community living, in relation to their relative's most recent hospital admission. Using the model of the narrative interview (Bauer & Gaskell, 1996), questions were grouped in chronological order:

- The planning and preparation for discharge
- The discharge day
- The days/weeks after discharge

The interview began with some general questions to give context to their experiences, collect some demographic information and help develop rapport.

2.3.3. Procedure

One-off in-depth interviews were carried out at the carer support services. These were felt to be comfortable settings for participants and were deemed adequately accessible. The mean interview length was 89 minutes (range 59-119 minutes).

Before the interview started participants were shown the participant information sheet again (see Appendix O) and given the opportunity to ask questions. Participants were then asked to sign the consent form (see Appendix P). Interviews were recorded on a digital audio recorder. The interview schedule was used to guide the interview but was used in a flexible manner. The researcher worked to bracket pre-existing thoughts and ideas to ensure that the participant's world was the sole focus of attention (see section 2.3.4.1). After the interview participants were debriefed (see Appendix R).

2.3.4. Analysis

After each interview the digital recording was transferred onto a password protected computer and then transcribed verbatim with guidance from Smith *et al.* (2009). Participants were given a pseudonym and all personally identifiable information was removed to ensure anonymity. Each transcript was then analysed using IPA, following the steps provided by Smith *et al.* (2009) (see Table 2.3).

Table 2.3 Analytical processes used to guide IPA (Smith *et al.*, 2009, p. 82-101).

Analytical stages	
1	Reading and re-reading
2	Initial noting
3	Developing emergent themes
4	Searching for connections across emergent themes
5	Moving on to the next case
6	Looking for patterns across cases

After engaging in stages one and two (see Table 2.3), linguistic and conceptual comments were made in the right-hand margin of the transcripts and analysed to identify emergent themes (noted in the left-hand margin) (see Appendix S for example). The next step involved structuring, organising and clustering the themes under super-ordinate conceptual headings. Once completed for each transcript, a summary table of the super-ordinate and sub-ordinate themes, along with illustrative excerpts was developed (see Appendix T for example). Using the summary tables for each case and returning to the transcripts where necessary, patterns across cases were then identified. Finally a master table was produced displaying how the themes incorporated from all the interviews were nested within super-ordinate themes (see Appendix U for an example). This was then written in narrative form, supported by verbatim extracts from the participants.

2.3.4.1. Validity and quality

Like any research, qualitative studies must adhere to appropriate quality checks. Smith *et al*. (2009) recommend referring to Yardley's (2000) criteria for assessing quality. These include: sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. These have been considered carefully and followed throughout the research process.

To ensure rigour in the current study, supervisors and colleagues with experience using IPA read transcripts and discussed emerging themes and connections with the principal researcher, referring back to the participants' accounts. Additionally, one of the transcripts was coded in full by a peer and this was checked alongside the principal researcher's initial notes to highlight significant issues that may have been missed.

Transparency was enhanced by a commitment to 'bracket' existing assumptions and understandings, as recommended by Elliot, Fischer and Rennie (1999). To uphold a reflexive stance, a journal was kept throughout the research process and assumptions, preconceptions, impressions and initial thoughts about participants were recorded. Some of these reflections form part of the Reflective Paper in

Chapter 3, which also considers the subjective position of the researcher. The principal researcher and a peer also conducted a bracketing interview using the interview schedule. Rolls and Relf (2006) argue that bracketing interviews are particularly effective in raising unconscious material and amplifying reflexive capacity due to the presence of an ‘other’.

2.3.5. Ethics

This study was conducted within the ethical framework provided by the codes of ethics and conduct of both Coventry University (based on guidance published by the UK Research Integrity Office, 2009 and the Research Councils UK, 2009) and the British Psychological Society (BPS, Code of Human Research Ethics, 2010). Ethical approval was sought and given by the ethics committee at Coventry University (see appendix H & I), and this was deemed satisfactory for conducting research within the two carer support services (see appendix J & K for confirmation).

2.4. Results

Three super-ordinate themes emerged from the data: *‘Being out of the loop’, ‘Getting back on track’* and *‘It’s all down to me’*. Figure 2.1 presents the thematic structure of the results which will then be qualitatively described, illustrated by extracts from participants’ transcripts. Three dots (...) appearing in the quotations indicates omitted text.

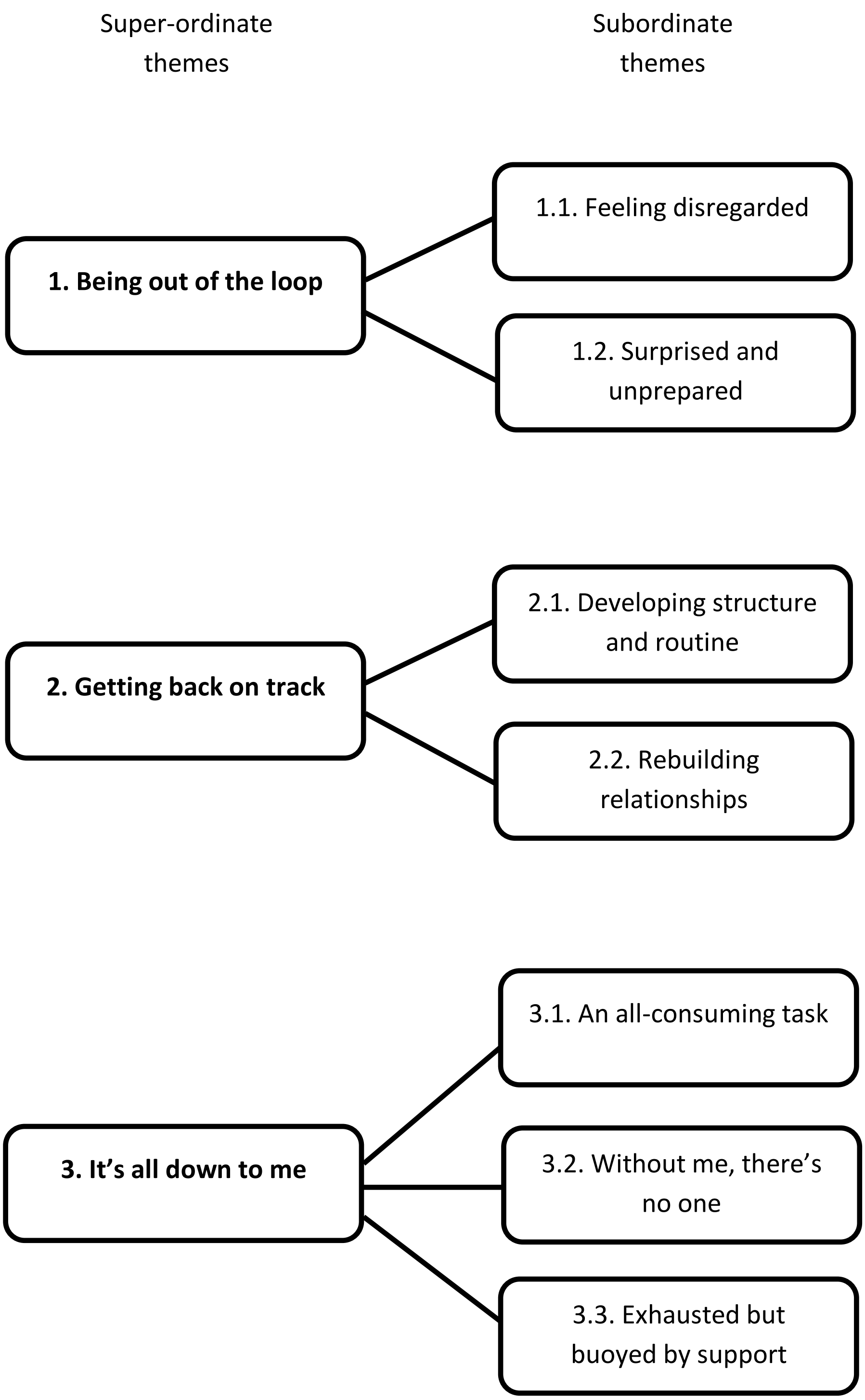

Figure 2.1 Compositional structure of IPA themes

2.4.1. Super-ordinate theme 1: 'Being out of the loop'

A pervasive theme across all carers' accounts was 'being out of the loop' throughout the discharge process. They described lacking information about, or involvement in, their relatives' care. As a result carers appeared to feel disregarded, not listened to and not valued. 'Being out of the loop' added to feelings of being unprepared for the point of discharge.

2.4.1.1. Subordinate theme 1: Feeling disregarded

A dominant theme was feeling disregarded as a mother, wife, daughter or sister. This experience was engendered through 'being shut out' of their relatives' care, in terms of the giving and receiving of information. Carers' accounts indicated that they were not offered a coherent explanation of their relatives' care plan and/or diagnosis.

> *"I think there should be someone to sit and talk…to people that care…there needs to be someone there to explain that person's illness"* [Brenda, line 732]

> *"I think they should have said…this is what we are hoping will happen…they are going to do this…they can't tell me how long…but they will monitor…*[so] *you've got some sort of plan in your head"* [Helen, line 1166]

In seeking information, carers were confronted by the issue of confidentiality. The way confidentiality was interpreted by mental health staff was experienced by carers as obstructive and unhelpful.

> *"They expect us to support them and care for them…they're not being fair because they don't let you know anything…I think you need some medical guidance"* [Margaret, line 23]

> *"When all this patient privacy was introduced which I agree with…I can understand that needs to be respected but from the carers' perspective it's extremely unhelpful"* [Elaine, line 366]

Additionally, carers felt there was limited opportunity to provide their 'expert' knowledge and a perspective on the care plan.

> *"I have never been interviewed…*[they] *never really know the real Katie they haven't got anything to compare"* [Dianne, line 1550]

> *"When Paul was in hospital I asked for…some supported housing…that all got brushed under the table he's coming home now you know"* [Brenda, line 699]

> *"Doesn't matter what…the family circumstances are they'll just listen to the patient"* [Elaine, line 423]

Margaret summarises her experience of feeling disregarded, with staff not seeming to value her views and treating her dismissively.

> *"They didn't want me there…he walked straight past me as if I didn't exist…they were taking no notice they were just talking to one another…there's no point you coming* [to ward round]*…I just felt they thought I was a nuisance…I'd gone over just purely to be with Jane in that room"* [Margaret, line 378]

Margaret's account reveals her feeling of being judged negatively for her efforts to be involved in her daughter's care and a need to defend her actions. Elaine seems to share this perspective, fearing the repercussions if she were to put her 'head above the parapet', thus she opts for taking a position of passive acceptance.

> *"If you start moaning...they'd* [mental health staff] *take it out on…my sister…I've known that happen quite a lot…I had to sort of go along with it really"* [line 307]

In contrast to the other carers, Stephanie appeared to have more belief in her right to be involved and listened to, *"I need to know…to help my mum"* [line 791]. Stephanie was the youngest carer interviewed and perhaps had more strength, as opposed to the others who presented as emotionally fatigued.

2.4.1.2. Subordinate theme 2: Surprised and unprepared

The point of discharge epitomised carers' experiences of 'being out of the loop' as they were given little or no warning. Consequently carers were taken by surprise and did not feel ready for their relatives to be discharged. This is captured in the extract below.

> *"They just suddenly come home they land then that's it…like out of the blue…how do I treat her what do I do"* [Dianne, line 1615]

Carers conveyed the importance of being given an opportunity to prepare and feel emotionally 'ready' for discharge. Stephanie described needing time to 'brace herself' for taking back responsibility of her mum's care.

> *“I wanted to sort of like mentally prepare myself for her to be home…It’s me that’s gotta look after her…I just wanted to make sure I was strong enough sort of thing”* [Stephanie, line 524]

In a practical sense, being ‘out of the loop’ and having little or no notice about the timing of discharge, left carers feeling inadequately qualified to take on the caring responsibility and vulnerable.

> *“A bit more reassurance…like having a telephone number…I’d have felt safer because I know I’ve got someone to contact if anything goes wrong…I don’t know what to do…how to deal with it”* [Dianne, line 1475]

2.4.1.3. Super-ordinate theme 1: Summary

This theme reflects carers’ overwhelming sense of being left out of the discharge process. Carers were largely not involved and not consulted. Consequently carers were surprised and unprepared by the discharge as it came ‘out of the blue’. They seemed to be struck by a surge of responsibility, which had not been soothed by the reassurance of adequate knowledge and information.

2.4.2. Super-ordinate theme 2: ‘Getting back on track’

There was a strong sense within carers’ narratives that discharge triggered an urge to restore normality and safety, despite their sense of fear. Their efforts to achieve equilibrium were demonstrated by instigating routine and re-connecting with their relative.

2.4.2.1. Subordinate theme 1: Developing structure and routine

Carers’ narratives indicated that they proactively developed structure and routine to regain some sense of safety and control.

> *“I tried to set up a new routine…I said…you’re not allowed to get out of bed ‘till nine…to give her some sort of structure…she sticks to it now…things are getting a lot better with things like that”* [Stephanie, line 699]

For Stephanie, creating order and routine seemed to help her manage the overwhelming nature of the caring task.

> *“I cooked mum meals every day…I gave her all her tablets and I’ve got into a routine of doing that now so it’s fine”* [line 751]

Helen described maintaining family traditions to help her feel life was ‘on track’ again.

> *“We’ve always had a bonfire party for her birthday…so that will be quite nice”* [Helen, line 835]

A similar sentiment was shared by Dianne, who conveyed the value of giving purpose and structure to her daughter’s life. The outings she described had special significance as they reflected what ‘they used to do’ and so signified a return to normality. For Brenda, this sense of equilibrium seemed to be prompted by the discharge itself as it represented her son being ‘back where he belongs’.

> *"We've been to the* [location] *since she's came out we've been to* [location] *…we're having nice days out again…to get her out and about"* [Dianne, line 243]

> *"I wanted him home…I was just glad he was out of hospital really"* [Brenda, line 601]

Margaret also expresses the significance she places on her daughter being occupied and having routine and structure in her life.

> *"It* [the day centre] *gave her meaning…*[before] *she never got washed and dressed…now she gets showered and dressed…there's a purpose"* [line 668]

Carers' perceived responsibility to develop structure and routine seemed to be driven by fear of relapse. Therefore fixing and maintaining the 'rules for living' was crucial for mutual well-being.

> *"I've gotta keep her going and active you know because she's gonna get bored and I don't want her…ever…to go back to…having a drink you see"* [Dianne, line 1666]

> *"Well let's go and just have a walk praps have a coffee but something to try and get him out of bed"* [Helen, line 521]

2.4.2.2. Subordinate theme 2: Rebuilding relationships

Another important element of 'getting back on track' involved the rebuilding of the relationship between carer and relative. There was a sense in all the accounts that during the pre-admission phase carers had experienced their relative as disturbing and frightening. It seemed that the relationship had been hurt and discharge enabled the healing and reconciliation process to begin. This involved proactively spending time together and beginning to see the ‘real person’ once again.

> *“Her personality is coming through a bit more…we’ve become closer for it…we try and make a point of walking the dogs together…we’re enjoying it together”* [Stephanie, line 720]

> *“Underneath you keep thinking that real person…is there still”* [Helen, line 303]

> *“I’ve* [Dianne’s daughter, Katie] *said horrible things about you* [referring to Dianne] *they’re not right I* [Dianne] *said well it’s in the past now don’t worry about it…you’re like you are now and you’re beautiful I’ve got my Katie back...we are going through a nice time now”* [Dianne, line 1174]

In the healing process, carers described their relatives conveying empathy and positive regard towards them. This contrasts with carers’ feelings during the pre-admission phase, that their relative’s perceived them as an ‘enemy’, who had failed them.

> *“He was concerned about problems for me and how much work it was for me”* [Helen, line 1048]

> *“She put her arms round me…and she said…what a lovely mum I’ve got”* [Dianne, line 1172]

> *“I think she appreciates me a little bit more”* [Stephanie, line 770]

The contrast in carers' use of language pre and post discharge is further evidence of a movement from detachment to togetherness. When recalling the pre-discharge period carers seemed to view their relative as belonging to a new 'group' (i.e. those with a mental illness) and in doing so regarded them as different and distant, in keeping with an image they held of their relative being a 'stranger'.

> *"So when **they're** going through that mental stage **they're** not always telling the truth"* [Dianne, line 1548]

In Helen's externalisation of her husband's illness, there is a sense of her separating from his illness and thereby him.

> *"I just feel it's wrong that somebody else should have to look after **this**"* [Helen, referring to her husband's illness, line 1036]

In contrast, carers' use of language in the post-discharge period, is markedly more unifying, and creates the image of the carer and relative being alongside one another and 'in it together'.

> *"We have worked through it"* [Helen, line 490]
>
> *"I'm her mother, her friend"* [Margaret, line 1394]
>
> *"I think it's good 'cos we're working together now to make things the way they should be"* [Stephanie, line 779]

2.4.2.3. Super-ordinate theme 2: Summary

This theme indicated that for carers, the point of discharge triggered the opportunity to regain normality, routine and predictability after a period of chaos and upheaval. There was a sense of wanting to forgive, move forward and enjoy life again.

2.4.3. Super-ordinate theme 3: ‘It’s all down to me’

Evident throughout carers’ narratives was their experience of the caring task in the post-discharge period as intense and relentless. The task weighed heavily, in part because of their sense of holding sole responsibility. Consequently, carers were left with an overpowering experience of emotional and physical fatigue but they were ‘kept afloat’ by the personal support they received.

2.4.3.1. Subordinate theme 1: An all-consuming task

Carers recounted the caring task, from the point of discharge, as all-consuming. They described their role as the ‘protector’, closely supervising and monitoring their relative, as though they were, *“looking after a baby”* [Stephanie, line 648].

> *“She wasn’t eating…I said well you’ve got to have something…I watch her I keep an eye on her”* [Margaret, line 502]
>
> *“My life wraps around my son…you never really switch off…you’re always watching…you’ve gotta keep saying you taking your medication”* [Brenda, line 29]
>
> *“She has to take tablets every day…I watch her I keep my eye on her”* [Dianne, line 1479]

Due to the carers’ total preoccupation with the task, it seemed that they constantly prioritised their relatives’ needs, burying their own thoughts and feelings.

> *"I have to be the strong person in it all…if I get upset it's gonna upset mum"* [Stephanie, line 658]

> *"He just sits there and cries…I wanna cry"* [Helen, line 559]

Carers seemed to only escape the all-consuming nature of the task once out of the physical presence of their relative. Stephanie and Margaret describe their need to plan breaks and time to pursue their own interests.

> *"We've come to the arrangement I have one night a week where I go out…as long as I get my one day where we have a break from each other…gives me my bit of freedom"* [Stephanie, line 151]

> *"I couldn't do my line dancing or anything else like that because…there were no…full days…so…I've gone back now I've made myself go back* [Margaret, line 844]

2.4.3.2. Subordinate theme 2: Without me, there's no one

Carers described having sole responsibility for the care of their relative because there was no-one else; family, friends, or mental health services. They conveyed an image of themselves and their relatives together in their own bubble, feeling isolated and trapped.

> *"I get frightened if anything happens to me who's gonna look after her…'cos really she's completely…on her own"* [Dianne, line 309]

> *"That's all…that's the only input…see the doctor every three to six months…not nothing else"* [Brenda, line 416]

The extracts below demonstrate the heavy weight of ‘holding’ sole carer responsibility.

> *“I just worry that I might find her a bit late* [following a suicide attempt] *you know then obviously I lose my mum sort of thing”* [Stephanie, line 145]

Brenda powerfully expresses the risks of ‘letting go’, due to her sense that her son’s wellbeing will be seriously compromised and there will be no one there for him.

> *“With mental illness what d’ya do chuck them onto the street and then where will he end up…‘cos there ent no…support out there…they’re left on their own and then they get more voices in their head…take me and the family away from him and he will be institutionalised…in a mental health unit”* [line 611]

There seems to be a pressure derived from duty and love to take on the caring responsibility. Carers all identify their sense of responsibility as inherent in their kinship identities, therefore seeming to hold the view that no one else *should* care for their relative.

> *“When we got married it was a case of…in sickness and health”* [Helen, line 790]
>
> *“It isn’t as though you’re paid to do this we’re just loving our children”* [Dianne, line 1734]
>
> *“She says well you shouldn’t have to look after me and I’m like well you brought me up”* [Stephanie, line 661]

There was one marked exception to the sense that carers were alone in their endeavour. Margaret was the only carer who described in any detail the support in place for her relative after discharge. This was a highly significant experience for Margaret as it considerably reduced her fears of discharge and alleviated the pressure of her caring responsibilities.

> *"Much better yes because they'd done a plan…I think it's marvellous…do you realise you've got something every single day and they'll look after you"* [line 659]

However, this support was transitory and there were no further plans in place. The positive impact of sharing responsibility was short-lived and seemed to merely delay the reality of bearing sole responsibility. Margaret expressed being on the edge of another daunting transition.

> *"That's coming to the end and I'm terrified what might happen…for her sake please don't let her get down the swanny again…I just wish she'd had a bit more support instead of cutting down the support"* [line 1121]

2.4.3.3. Subordinate theme 3: Exhausted but buoyed by support

As a consequence of the huge pressure carers described, there was an overwhelming feeling of exhaustion, not only in carers' accounts but also in their demeanour throughout the interviews. Carers were drained by the intensity and relentlessness of their role. Some felt they had sacrificed themselves and their lives for long enough.

> *"Everything revolves around…Hannah…and now it's my turn…I was a carer at work as well so I feel as if I've had enough of caring…I feel I need some life of my own now at forty eight...done my bit if you like"* [Elaine, line 668]

> *"Now I'm getting older I feel like I'm burning out…it's took its toll on me…the next time I don't think I could cope with it"* [Brenda, line 26]

> *"As I'm getting older…I don't feel I have any more to give…I just feel…empty…as if I've given everything and I've got no reserve…I don't feel…I can do anymore…sounds wicked but I'm too tired now"* [Margaret, line 361]

Carers feared a future crisis and doubted their capacity to 'cope' with a 'next time' because they were exhausted and felt the heavy burden of responsibility. Participants conveyed some sense of 'wanting out'. Helen appeared to be using her wish for freedom as a kind of threat and Brenda's disclosure indicated a sense of shame.

> *"He kept saying I love that feeling of being so elated I said you can have that anytime you want but I will not be here another time to help you with this I can't do it again"* [Helen, line 421]

> *"I don't care if he takes ill again he's not coming back home…think I can say that…hard I've only told you…I don't think I'd tell anyone else"* [Brenda, line 797]

Carers' experience of exhaustion and of feeling unable to cope seemed to be moderated by the highly valued personal support they received from professionals. The powerful and emotionally laden language and metaphors used to describe this support, is evidence of its remarkable significance and meaning. In recalling their experiences of support, carers created images of being 'rescued', 'saved' and 'thrown a lifeline'.

> *"The best thing that's ever happened to me...I felt a new woman with her…really she's a wonderful prop"* [Margaret, line 704]

> *"In the meantime they send* [carer support worker] *to me who was my lifesaver she was beautiful"* [Dianne, line 1001]

> *"Brilliant social worker…beautiful person…she was golden…she'd bend over backwards to help you…she was an angel"* [Elaine, line 272]

2.4.3.4. Super-ordinate theme 3: Summary

For carers, the discharge represented and triggered the resumption of their caring role. This was experienced as all-consuming due to their feeling of responsibility to ensure their relatives' wellbeing. The pressure of this caring task was exacerbated by their feeling of holding sole responsibility, which seemed to lead to feelings of loneliness and isolation. As a consequence of the intensive role, carers felt exhausted and doubted their capacity to cope. The challenges and difficulties posed by the caring task seemed to be mitigated by support, which was experienced as highly meaningful and significant.

2.5. Discussion

The study's primary aim was to explore carers' experiences of the discharge process from inpatient mental health services. There were also two secondary aims: to consider; the family member's sense of their role during this process, and the factors they perceived important in making a positive or negative difference to their experience.

The intention of the research was to give voice to an idiographic, purposeful sample, to shape an understanding of their experiences and consider how their narratives might inform service provision. Therefore the current analysis should not be considered to reflect the experiences of all carers or represent truisms regarding the phenomenon of hospital discharge.

Three themes emerged which will be discussed in relation to the literature and the research questions, before considering the clinical implications, limitations and recommendations for future research.

2.5.1. Exploration of themes

Super-ordinate theme 1: 'Being out of the loop' captures carers' experiences of their level of involvement in the discharge process. Family members reported feeling disregarded, excluded and undervalued by mental health staff. Carers felt surprised at the point of discharge because it came 'out of the blue', leaving them feeling unprepared and vulnerable. Carers' sense of needing time to adjust to, or prepare for, discharge was also identified by Clarke and Winsor (2010) and Hickman (2011).

Carers in the current study reported having little information about, or involvement in, their relative's care or the discharge plans. This suggests that carers' experiences did not meet either the information/explanation, or the consultation level of user involvement (Hickney & Kipping, 1998). In spite of this experience, the majority of carers seemed accepting of their level of involvement. Sometimes this seemed to be driven by a fear that there might be negative repercussions for themselves or their relatives. There was also a sense that carers lacked awareness, knowledge or understanding of their rights or entitlement to be involved in their relatives' care. Most participants had been caring for a number of years and may have habituated to feeling ignored or shut out by services. Therefore carers' position in relation to staff may reflect a state of learned helplessness (Seligman, 1975).

The experience of carers feeling excluded from services has been highlighted elsewhere. Cleary, Freeman, Hunt and Walter (2005), Jubb and Shanley (2002) and O'Brien and Cole (2004) found that carers experienced feeling distanced and excluded from the care planning process within mental health services. The current findings were also mirrored by Wilkinson and McAndrew (2008), who reported that carers felt they were not recognised or valued by mental health staff. Although best practice stresses the value of proactively promoting a therapeutic alliance between staff, carers and patients (NMHDU, 2010), this seems to be far from reality for participating carers.

Being outside 'The Triangle of Care' (NMHDU, 2010) meant that carers were given little or no guidance or reassurance at the point of discharge, leaving them feeling poorly equipped and unskilled. This fostered a sense of anxiety because carers did not seem to know what to do or how to 'be' with their relative. Similarly, Wilkinson and McAndrew (2008) found that carers questioned their ability to care upon discharge due to feeling uninformed.

Super-ordinate theme 2: 'Getting back on track' explores carers' active responses to their relatives' discharge. This involved proactively developing structures, routines and organising opportunities to 'be alongside' their relative. This response seemed to be, in part, driven by their fundamental need to feel safe (Maslow, 1943), following a period which had threatened their sense of safety.

Carers in this study also reported feeling responsible for instigating structures and routines for their relatives, in an effort to keep them well. Carers described supporting their relatives in keeping active, having a structure and purpose to their day, sleeping and eating well, and maintaining their medication regime. In the absence of professional guidance at the point of discharge, carers seemed to instinctively draw on their in-built coping strategies (Early & GlenMaye, 2000), confirming their position as an 'expert by experience' (Addington, Addington, Jones & Ko, 2001).

Carers in this study seemed to be engaging in aspects of 'recovery-orientated practice' (Anthony, 1993). Despite this, carers felt uncertain and anxious about their caring strategies and expressed a continuing need for knowledge and reassurance. Therefore carers seemed to underestimate the part they were playing in their relatives' recovery. Parr (2009) argues that carers are "well placed to influence the progress and direction of recovery because of their intimate knowledge of the person they are supporting" (2009, p. 4). However Dixon (2000) describes there being a "separation of family from the recovery movement" (2000, p. 444). This seems to reflect carers' experiences in the current study on the basis of their reported feelings of exclusion.

The second aspect of 'getting back on track' involved carers' drive to rebuild their relationship with their relative. Carers held traumatic memories about the deterioration of their relatives' mental health. These remained raw and left carers feeling that relationships had been ruptured. Carers described proactively securing space to spend time with their relative. This, coupled with their relatives' positive responses, seemed to lead carers to believe in a rediscovery of their connection. There was a distinct sense of hopefulness in carers' descriptions of what appeared to be the beginnings of a healing process in the relationship. Carers' sense of hope has been found to be essential to recovery (Kirkpatrick, Landeen, Woodside and Byrne, 2001; Darlington & Bland, 1999). However, carers' hopefulness did not extend to their attitude about their relatives' recovery, where they viewed relapse as inevitable. Perhaps this is not surprising as they are likely to feel more confident in rebuilding relationships than managing mental illness.

Super-ordinate theme 3: 'It's all down to me' relates to carers' emotional responses to caring for their relatives on discharge. Carers described their role as totally preoccupying, exacerbated by a sense of being alone in the caring task, leading to feelings of emotional fatigue. However, carers described the fleeting personal support they received as being 'lifesaving' and the supporters as 'angels'.

Carers in this study described anxiously supervising and monitoring their relative, seeming to subsume their own needs; the task was likened to caring for a new baby. It was as though for carers, the caring endeavour was akin to the role of a mother as a 'container' or 'holding' figure for her infant (Bion, 1962; Winnicott, 1945). This highlights carers' perceptions of vulnerability, fragility and dependency in their relatives at the time of discharge; thus seeing their adult relatives as children. The need for carers to protect this 'vulnerable child' raises issues around dependency/independency, holding on/letting go, which are further complicated by carers' distinct fear.

In contrast to the notion of carers as 'containers' for their relatives, carers reflected a sense of abandonment by services around them. This is evidenced by carers describing feeling isolated, solely responsible and caring alone, in the vacuum created by discharge. Similarly, carers in Plank *et al.*'s (2012) study reported 'being responsible for everything' following their relatives discharge from hospital. Carers' narratives revealed a notable absence of meaningful or sufficient follow-up support by mental health services. The feeling of receiving inadequate support on discharge has been previously described by both carers (Hickman, 2011) and patients (Cutcliffe *et al.*, 2012).

Carers experienced the pressure of the caring role as exhausting and they doubted their capability to cope, indicating a risk of high stress (Lazarus and Folkman, 1984). Participating carers may have been especially vulnerable to stress as they were in a process of adjustment to change (Holmes & Rahe, 1967). However, the caring role in general has been strongly associated with feelings of burden (e.g. Ostman & Hansson, 2004) and the impact on carers own mental health has been well documented (Shah, Wadoo & Latoo, 2010), highlighting carers' own recovery needs (Kelly, 2009).

Schlossberg's (1981) transition theory suggests that support is especially crucial during transition to aid adaptation and achieve a sense of mastery. Although some carers in this study described the support they received as 'lifesaving', this seems to be contradicted by their simultaneous descriptions of being alone and not held.

2.5.2. Clinical implications

Above all the issues highlighted by this research, of most concern was the significant discrepancy between discharge policy and practice. Participating carers felt far from being “expert partners in hospital discharge” (ADASS, 2010, p. 4). Although IPA research does not seek to generalise findings, this shortfall does represent a potential risk to patients, carers and mental health services, which therefore demands exploration. For patients the success of their discharge is threatened, carers’ health and well-being is jeopardised and stretched mental health services risk alienating this crucial arm of their service. Therefore services need to understand ‘The Triangle of Care’ (NMHDU, 2010) and make it real and meaningful for all sides.

There were a number of factors embedded within carers’ narratives which seemed to evidence the absence of an expert partnership. On this basis, what follows is a summary of some opportunities for strengthening carers’ role in ‘The Triangle of Care’ (NMHDU, 2010):

- Having knowledge of, and involvement in the overall discharge plan
- Having open lines of communication
- Being sufficiently prepared, equipped and supported
- Feeling ‘free’ to seek information, challenge and make demands

The carers outcome strategy (DoH, 2010) highlights that carers should be involved in “planning and designing hospital discharge arrangements” (2010, p. 10). Therefore, with the patient’s agreement, every effort should be made by staff to involve and include carers in all stages of the discharge planning process, in an open, welcoming, non-judgemental and flexible manner.

The current research stresses the importance of training hospital staff in carer engagement, with a particular focus on inclusion and communication. For example, there is a need to ensure that carers have full information about arrangements for home leave and discharge. In relation to confidentiality and information sharing, the current research supports the development of practice protocols, and making contracts with involved individuals that include what will be disclosed and how , with the understanding that this may change over time.

While there is a process in place for preparing patients for discharge (DoH, 2003), this research has identified that carers also need to be prepared in a practical and emotional sense. The hospital admission could be used to provide carers with their own package of support. Shah *et al*. (2010) considered the important role for health-care professionals in helping carers enhance their coping skills, supporting existing skills and facilitating new ones.

The current research would support the dissemination of information about carers' rights and entitlement to be involved in their relatives' care, with time for carers to discuss this with staff and ask questions.

In summary, it is well-documented that the part carers play in their relatives' care should be highly recognised and valued (e.g. DoH, 2010). The achievement of the above proposals would both strengthen the position of carers as "expert partners in hospital discharge" (ADASS, 2010, p. 4) and increase the chances of a successful transition.

2.5.3. Limitations

The present study utilises a small and purposeful sample consistent with IPA guidelines. However some sampling limitations should be noted. Four of the six participants were over sixty and three of the participants were mothers. Therefore this research may not as accurately represent the experiences of younger carers or sibling and spouse carers. Furthermore, the composition is limited by the absence of Black and Minority Ethnic participants.

Recruiting through carer support services may have resulted in bias within the sample and data. For example, there may be differences in the profiles of those carers who access and engage with carer support services and those who do not. Additionally, carer support workers may have been influenced by their knowledge and experiences of the carers they selected. Furthermore, participating carers may have been influenced by their awareness of the carer support services' involvement in the study.

Finally, due to practical constraints the analysed data was not fed-back to all participants. Respondent validation is not standard practice in IPA research (for reasons outlined in Smith *et al*., 2009), though it can help to increase the authenticity of findings.

2.5.4. Future research

Future phenomenological research could approach the sampling limitations identified above through further targeted recruitment, or by exploring a broader range of carer profiles. Research aiming to explore the transition process further might be achieved by interviewing carers at specified time periods before and after discharge.

Considering the challenges and risks associated with discharge from inpatient care, there is a dearth of qualitative research in this area. This was the only paper identified which considered the discharge process specifically from the perspective of mental health carers. Therefore further exploration of all perspectives within the patients' 'system' may provide invaluable insights into strategies for increasing the chance of a successful transition and reducing risk.

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Chapter Three: Reflective Paper

Research facilitating personal insights into the world of a carer: Loss and grief in caring

In preparation for submission to *Reflective Practice* (see Appendix V for Author Instructions)

Overall chapter word count (excluding references): 3 382

3.1. Introduction

This thesis has investigated discharge from mental health inpatient care for both patients and carers. This final paper is an opportunity to reflect on this process. It will focus on my insights into the world of those caring for someone with a severe and enduring mental illness.

Although I developed my initial understandings about the role of carers during clinical work prior to clinical training, it is the research process that has facilitated insights that have much greater depth and richness. This paper will focus on one in particular, the area of loss and grief inherent in caring. I found this to be a particularly powerful aspect of many carers' stories, and one which, in my experience, is an often overlooked aspect that needs greater attention.

As this research journey draws to a close, it is the strong emotional reactions I experienced during the interviews with carers which resonate most powerfully and will no doubt endure. I end this paper by considering the ways in which taking the role of a researcher as opposed to a clinician may have facilitated my connection to the emotion within carers' stories, and how I might be able to use these reflections to improve my future clinical practice.

3.2. My route into the world of carers

My most prominent experience of, and contact with, carers prior to this research was when I was an assistant psychologist in a multi-disciplinary team working with those with severe and enduring mental illness.

The majority of the clients I worked with lived with their families, with whom I had minimal contact. The therapeutic work I delivered was almost exclusively one-to-one, with little discussion about the potential benefits of systemic work. At the time, I did not question this approach. However, I was greatly concerned by my sense that within the team, unhelpful and negative hidden values and assumptions were held about carers (Schein, 2004).

When carers shared their experiences of interacting with services during this research, I was swiftly taken back to my time as an assistant psychologist and regrettably identified with much that they said. I felt embarrassment and shame, firstly for my sense of responsibility for their treatment due to my affiliation with mental health services in general, and secondly for being witness in the past to the types of encounters carers described, yet having done nothing to challenge this with colleagues at the time.

Looking back to my time as an assistant psychologist, I distinctly remember feeling very uncomfortable as a bystander and sharing my concerns in supervision. I came to the conclusion that what was missing was space or time, firstly to try to understand why a carer might be frequently phoning the office (for example), and secondly to consider the team member’s reactions and the impact this might have on clients and carers. These reflections led me to empathise, respect and acknowledge carers’ roles and gave me the incentive to devise a piece of research which would give carers a voice.

This prominent experience during my role as an assistant psychologist undoubtedly left its mark and therefore influenced my subjective position as a researcher. The bracketing interview I organised prior to interviewing provided an opportunity to reflect on these experiences and helped to bring issues to a more conscious level. My sense of carers’ negativity towards services was clear and with this awareness I was able to make efforts to ‘bracket off’ these issues to ensure that I was open to both carers’ positive and negative experiences. This is in line with the aims of IPA, to reflect on existing perceptions, memories and values but not to make them “disappear” (Smith, Flowers, & Larkin, 2009, p. 14) because these are “explicit and thus legitimate components of the enquiry” (Biggerstaff & Thompson, 2008, p. 17).

It has become clear since embarking on this research that although I came on this journey with insights, ideas and a perspective of carers and their lives, these were distinctly partial. This may in part be because I had not worked directly with carers. Although this is not particularly surprising given that most adult psychological therapy is delivered one-to-one and because services are client-centred, the result was a considerably limited sense of carers. This is highlighted in the extract below from my reflective journal written during the research process:

> *“I can feel myself getting more passionate about the carers’ position – the heartache, always being on edge, on call, anticipating the worst. I have been thinking about how I viewed carers before, I thought I had an understanding but I really didn’t…”*

Therefore my understanding prior to this research process was probably fairly superficial, and engaging in this study was my first opportunity to really hear, understand and appreciate carers’ perspectives, which, as I demonstrate, has led me to new discoveries and ways of thinking.

3.3. Loss and grief in caring

After completing each interview, there was undoubtedly a sense of achievement in being one step further along the research path, but my overriding feeling was sadness. I could intellectualise this sadness as being a reflection of the circumstances and life situations carers had found themselves in through no choice of their own, but my sadness was more akin to the quality of a counter-transference reaction (Freud, 1910). Carers' apparent projection (Freud, 1937) into or onto me had provided me with a greater sense of their mental state, the essence of which seemed, for some at least, to have been too unbearable to fully express. Given carers' fears of being unable to cope, the extent of their relatives' dependency on them and the context in which I was meeting them, protecting themselves from the magnitude of their sadness was understandable. However, acknowledging and working to further expand on what this counter-transference reaction might reveal about carers' mental states offered me a learning opportunity (Heimann, 1950).

In my efforts to understand more about carers' sadness, I listened back to each interview. It seemed that beneath the trauma conveyed within carers' stories were significant and numerous losses, the full expression of which was kept hidden. Of most relevance to my research question was loss associated with the separation of the hospital admission. However, there seemed to be many more fundamental losses that carers had been suffering since their relative first became ill. It may be that due to the complexity of these losses, the grief response is denied or not acknowledged. This may prevent carers from being able to engage with the support they may most require.

3.3.1. Defining loss and grief

In considering the concepts of loss and grief from a theoretical perspective, there seemed to be significant applicability to, and overlap with, the situations and life circumstances of the carers interviewed. Grief is the reaction to loss, which historically referred to irrevocable loss, or loss through death. However, grief and loss are now understood in broader terms, as demonstrated by Engel (1961) who described grief as “the characteristic response to the loss of a valued object, be it a loved person, a cherished possession, a job, status, home, country, an ideal, a part of the body” (1961, p. 18). Grief is also thought to accompany losses of dreams and wishes (Grayson, 1970; Shabad, 1989), which may reveal themselves over time, at different developmental milestones.

3.3.2. Carers’ expressions of loss and grief

On the basis of this theoretical understanding of loss and grief, I felt that there were numerous expressions of loss within carers’ narratives, some of which were more overt than others. There seemed to be two types of losses: those that were closely related to the crisis episode which prompted the hospital admission, and those that seemed more existential in nature. While the first appeared to be finite, in the sense that it had a clearer beginning and end, the second seemed more akin to Olshansky’s (1962) concept of ‘chronic sorrow’, the conceptualisation of loss as a process of realisation occurring over an individual’s life span. It struck me that underneath carers’ experiences of the discharge process was potentially a deep seated experience of loss.

Although there were a number of examples of loss within carers’ narratives, it was Helen’s story that really touched me. There was bitterness, anger, blame and a lack of compassion in Helen’s expression and tone when she talked about her husband. These feelings were markedly stronger and more extreme compared to the other interviews. In spite of Helen’s manner, my strong feeling when I was with her was sadness. I noted in my reflective diary feeling tearful during the interview. I wondered whether the anger was actually being used as a defence against connecting to her sadness, as in reaction formation (Bateman, Brown, & Pedder, 2010).

The losses that Helen described included; her identity as a wife, her husband (or at least the man she had chosen to spend her life with) and her hopes and expectations of what her life would hold. Ultimately, Helen seemed to be conveying the loss of her assumptive world (Parkes, 1988): the “assumptions or beliefs that ground, secure or orient people, that give a sense of reality, meaning, or purpose to life” (Kauffman, 2002, p. 1). With this she lost her sense of safety, which really highlights the true trauma of this loss. To Helen, or at least on that particular day I interviewed her, these losses were irrevocable.

In reflecting on Helen’s story, I wondered whether her response differed in part because she was a wife rather than, for example, a mother. There seemed to be an injustice in Helen’s description of her story which I did not sense during the other interviews. There was a sense of, “I didn’t sign up to this.” Perhaps the mothers also experienced this injustice on some level, but they had taken responsibility for caring, protecting and keeping their children safe since their birth, so to an extent they did ‘sign up to this’. In contrast, in Helen’s story there was a clear and distinct shift in her marriage after her husband became depressed, which was perhaps less applicable to the parents in my sample.

For me, Helen’s story, and to an extent the other narratives, brought into sharp focus how much about my life I take for granted and how quickly life can change. While my assumptive world helps me to feel secure and grounded, I wonder whether this sometimes prevents me from truly valuing what I have. I think Helen’s story was so powerful for me because it prompted me to reflect on my relationship with my partner, particularly since embarking on clinical training. The final year has been particularly all-consuming and I have relied heavily, both practically and emotionally, on the support of my partner. I have been relieved (in the short term) of some of my roles, tasks and responsibilities to enable me to focus on my work. While Helen’s story enabled me to truly value and appreciate this support, it also brought me closer to the fragility of life. It was a vulnerable feeling being in touch with how much I have needed my partner alongside me to manage this challenging time in my life.

3.3.3. ‘Nonfinite loss’ and ‘disenfranchised grief’

The fragility of life and feelings of vulnerability that I was in touch with gave me insights into the traumatic loss that Helen had endured. The losses she and other carers described are consistent with a much broader understanding of loss, the greatest significance of which is that the carer’s loss is not the result of a death. This is the essence of 'nonfinite loss', proposed by Bruce and Schultz (2001) to describe losses that are "contingent on time and dysnchrony with hopes, wishes, ideals and expectations" (2001, p. 32). 'Nonfinite loss' is experienced in the aftermath of events of varying intensities of trauma and disruption to our life pattern. They are viewed as "chronic in nature and the occurrence of these events is characterised by more or less degrees of unpredictability" (2001, p. 217). Using this framework to relate to carers of those with mental illness, the traumatic events could be the crisis points, which may then be followed by a period of stability. However, the impact of the crisis endures because of the uncertainty and unpredictability of 'the next time'.

The extract below from my reflective diary, written after my interview with Helen, summaries the complexity of 'nonfinite loss':

> *"So sad the loss that Helen feels, in one sense she says she doesn't have a husband anymore but in another, is committed to him"*

Helen has 'lost' her husband, yet he is still alive. Other carers also conveyed a sense they had lost something of their relative or something of their relationship with their relative. During the interview with Helen she told me that she had recently met up with one of her friends whose husband was killed in an accident, and she described feeling envious of her and then almost immediately remorseful and ashamed for admitting to this. I did not feel this to be malicious, but, to me, it felt as though she was conveying the relief that would accompany her husband's death, because it would enable, or even 'allow' her the opportunity to grieve and mourn, a process she feels unable or uncomfortable to engage in while he is alive. This highlights the complexity of grieving in 'nonfinite loss', because grief is often disenfranchised when there is no physical death to mourn (Bruce & Schultz, 2001). I wonder if Helen and quite possibly other carers are denying their right to grieve, a predicament termed ‘disenfranchised grief’ (Doka, 1989). They may therefore hide their emotions and bury their grief. Bruce and Schultz propose that the grief in ‘nonfinite loss’ is largely ignored.

3.3.4. What might carers need?

Part of my reason for reflecting and investigating in more depth the emotions of loss and grief was to raise the profile of this issue. It is quite likely that carers keep their feelings of loss hidden and buried, for the complicated reasons outlined above. However, I would argue that the ‘nonfinite loss’ carers have experienced and continue to experience, compounds their already challenging lives.

Bruce and Schultz (2001) outline a detailed therapeutic approach to grieving ‘nonfinite loss’. However, the carers I met did not seem to be particularly connected to their loss. Additionally, as with any therapeutic approach this may not be appropriate for all. However, carers may benefit from people around them having an understanding of the loss and grief that may be present in their lives. Carers may be thinking, or may have heard those around them saying, ‘it could be worse’, ‘at least your husband’s still alive’, serving to further entrench their feelings and prevent them from allowing themselves permission to grieve. However, if carers were alongside someone who legitimised and validated their loss, they may be more able to process their thoughts and ventilate their emotions. This may help them to grieve their losses and work towards adapting to a new version of life as Helen described:

> *"You know when somebody's died…it doesn't get better you just have to adapt your way of life and I think that's the same with this"* (line 849)

This process I have proposed relies on carers having a 'someone'. The majority of the carers I interviewed described the therapeutic relationship they had developed with their carer support worker in very positive terms, clearly valuing the support they offered. Therefore, where the support is available, carer support workers may be best placed to engage with carers' experiences of loss and grief, if and when, this feels appropriate.

3.4. Being 'free' to hear the carers' world

As I have discussed, the research I conducted offered me the opportunity to 'see' carers differently and learn about their lives in a much deeper way. I feel that this insight held greater power and meaning for me because of the emotional impact of each interview. I gained more than merely an intellectual understanding of carers' lives. The significance of this for me was that I felt more emotionally impacted by the carers I interviewed in my research capacity, than I have done when working clinically in any therapeutic encounter. It seemed that something about the research process itself enabled me to 'feel' the carers' stories differently.

Despite both therapy and social science research being essentially human endeavours, they have fundamentally different aims. Clients seek therapy because they are unhappy with something in their life and are looking for change. My role in this capacity is therefore to work with the client to bring about positive and lasting change. However, as a researcher, I was exploring, studying and gaining a greater understanding about carers' lives, but the aim was not to bring about change. Therefore I wonder whether by taking away the pressure or responsibility for being a catalyst for change, I felt a sense of freedom and could just 'be' with the carers I interviewed. I thoroughly enjoyed each interview, in part because I was able to purely listen, just offering prompts when necessary. The carers had no expectations that I would offer them anything, unlike in a therapeutic encounter; in a sense the 'contract' was much more straightforward.

This research process has enabled me to truly appreciate the power of listening and really 'being' with people, hearing and feeling their stories. In any therapeutic encounter I am engaged in multiple tasks simultaneously. I am listening and responding to clients, but I also have a huge array of questions in my mind, including what I should say next, what the client might need, the client's formulation and my expectations of the session, to name but a few. I am also paying attention to my emotional responses and what these might mean. Comparing this to my role in a research interview, it seems that many of these tasks take me away from the client and make it more difficult for me to be able to connect emotionally with them.

Having gained insight into this aspect of my clinical practice, it is important to consider how to utilise the insight to improve my clinical work. It is challenging in some ways because the inherent differences between research and therapy mean that I cannot completely 'forget' all my internal questions. However, perhaps part of the confusion relates to my stage of clinical training; I am nearing its end and trying to determine the therapeutic direction I wish to take. I am as yet undecided, so this may mean that internally during a therapeutic session there is no filter, I am questioning and considering issues of relevance to a whole array of therapeutic models. Therefore it is likely that my clinical work would improve by having a greater sense of therapeutic direction. The insights gleaned through the research process indicate that perhaps a more emotion focused model may be the best fit for me. Although I do not have access to the carers' perceptions of me, I felt that through connecting on an emotional level I was more able to empathise and access their internal world, which I believe is a crucial aspect of the therapeutic endeavour.

3.5. Conclusion

First and foremost, it was a real privilege to hear the stories that carers shared with me during the research process. I am keen to share my thoughts on their experiences and to help their voices be heard. In my contact with carers throughout the research process, it appeared that they were becoming tired of telling and re-telling their stories of being devalued, ignored and excluded because they felt they came to nothing. I therefore feel a strong sense of responsibility to do what I can to make the time that carers spent with me as worthwhile as possible. I have made strong links with the carer support services to enable the process of dissemination of my research to acute care services in particular.

In considering my clinical role, devising this research has provided me with a rather unique opportunity to understand a part of the client's system in some depth. I intend to use this perspective to aid my understanding of family systems in my future clinical practice and to promote, recognise and highlight carers’ needs amongst my colleagues in multidisciplinary teams.

3.6. References

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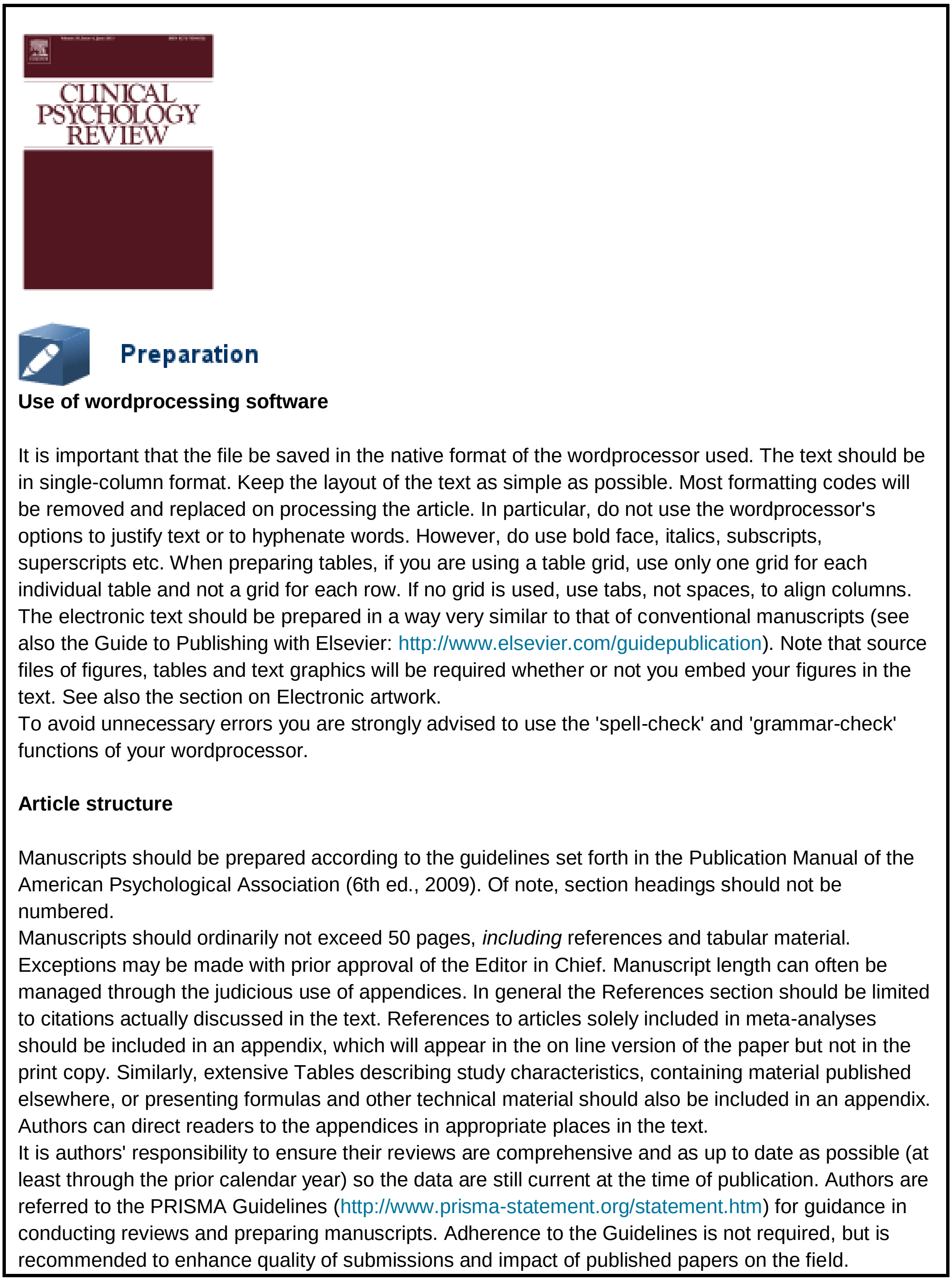
Appendix A

Author instructions for *Clinical Psychology Review*



Preparation

Use of wordprocessing software

It is important that the file be saved in the native format of the wordprocessor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the wordprocessor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier: http://www.elsevier.com/guidepublication). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic artwork.
To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your wordprocessor.

Article structure

Manuscripts should be prepared according to the guidelines set forth in the Publication Manual of the American Psychological Association (6th ed., 2009). Of note, section headings should not be numbered.
Manuscripts should ordinarily not exceed 50 pages, *including* references and tabular material. Exceptions may be made with prior approval of the Editor in Chief. Manuscript length can often be managed through the judicious use of appendices. In general the References section should be limited to citations actually discussed in the text. References to articles solely included in meta-analyses should be included in an appendix, which will appear in the on line version of the paper but not in the print copy. Similarly, extensive Tables describing study characteristics, containing material published elsewhere, or presenting formulas and other technical material should also be included in an appendix. Authors can direct readers to the appendices in appropriate places in the text.
It is authors' responsibility to ensure their reviews are comprehensive and as up to date as possible (at least through the prior calendar year) so the data are still current at the time of publication. Authors are referred to the PRISMA Guidelines (http://www.prisma-statement.org/statement.htm) for guidance in conducting reviews and preparing manuscripts. Adherence to the Guidelines is not required, but is recommended to enhance quality of submissions and impact of published papers on the field.

Appendices

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

Essential title page information

Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible. **Note: The title page should be the first page of the manuscript document indicating the author's names and affiliations and the corresponding author's complete contact information.**

Author names and affiliations. Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name, and, if available, the e-mail address of each author within the cover letter.

Corresponding author. Clearly indicate who is willing to handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that telephone and fax numbers (with country and area code) are provided in addition to the e-mail address and the complete postal address.**

Present/permanent address. If an author has moved since the work described in the article was done, or was visiting at the time, a "Present address"' (or "Permanent address") may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Abstract

A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

Abbreviations

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Footnotes

Footnotes should be used sparingly. Number them consecutively throughout the article, using superscript Arabic numbers. Many wordprocessors build footnotes into the text, and this feature may be used. Should this not be the case, indicate the position of footnotes in the text and present the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

Table footnotes

Indicate each footnote in a table with a superscript lowercase letter.

Figure captions

Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (**not** on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

Tables

Number tables consecutively in accordance with their appearance in the text. Place footnotes to tables below the table body and indicate them with superscript lowercase letters. Avoid vertical rules. Be sparing in the use of tables and ensure that the data presented in tables do not duplicate results described elsewhere in the article.

References

Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 1-4338-0559-6, copies of which may be ordered from http://books.apa.org/books.cfm?id=4200067 or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK. Details concerning this referencing style can also be found at http://humanities.byu.edu/linguistics/Henrichsen/APA/APA01.html

Citation in text

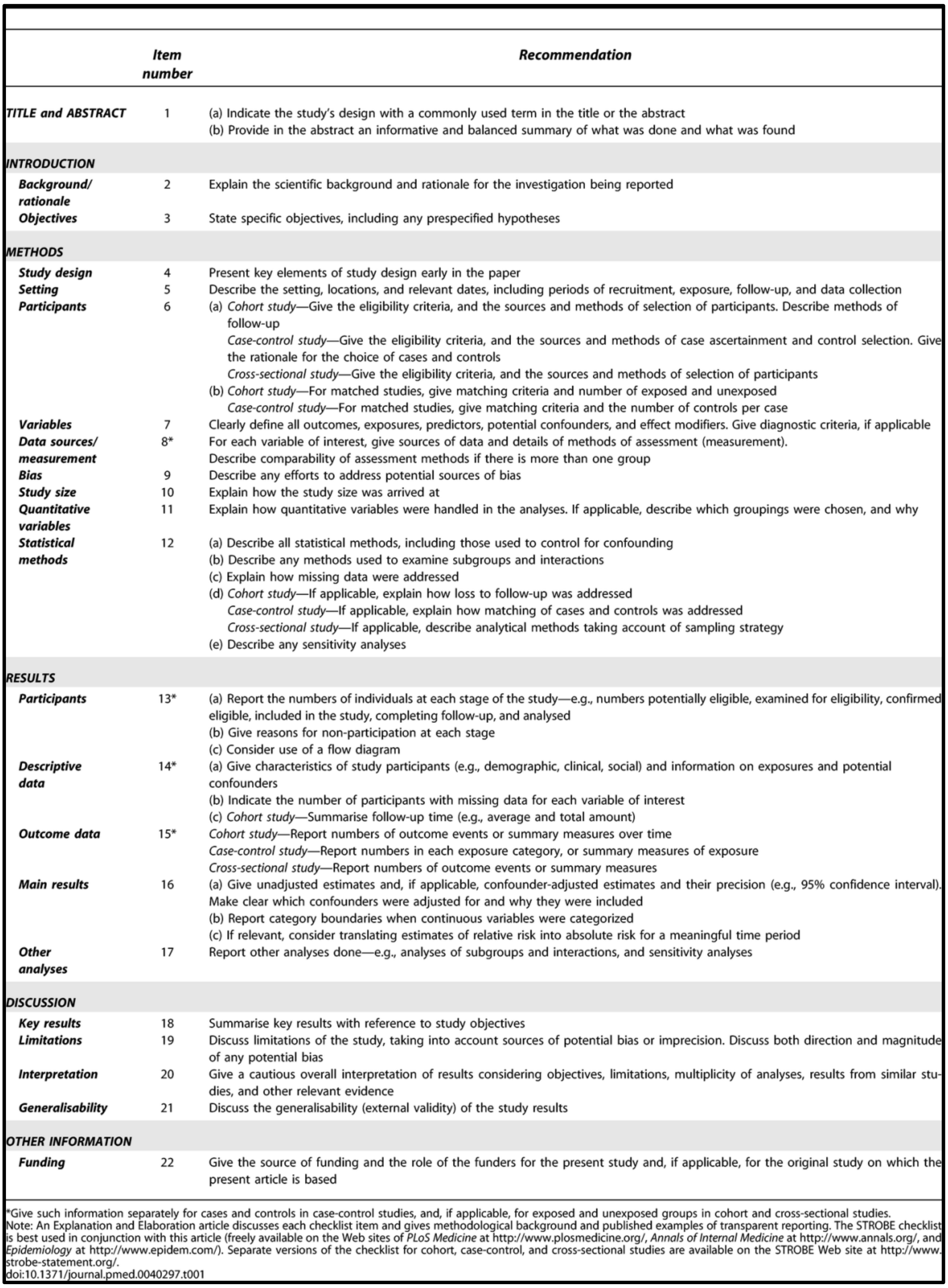
Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

Reference style

References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters "a", "b", "c", etc., placed after the year of publication. **References should be formatted with a hanging indent (i.e., the first line of each reference is flush left while the subsequent lines are indented).**
Examples: Reference to a journal publication: Van der Geer, J., Hanraads, J. A. J., & Lupton R. A. (2000). The art of writing a scientific article. *Journal of Scientific Communications,* 163, 51-59.
Reference to a book: Strunk, W., Jr., &White, E. B. (1979). *The elements of style.* (3rd ed.). New York: Macmillan, (Chapter 4).
Reference to a chapter in an edited book: Mettam, G. R., & Adams, L. B. (1994). How to prepare an electronic version of your article. In B.S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281-304). New York: E-Publishing Inc.

Appendix B

The STROBE statement



	Item number	Recommendation
TITLE and ABSTRACT	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found
INTRODUCTION		
Background/ rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
METHODS		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(a) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants (b) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses
RESULTS		
Participants	13*	(a) Report the numbers of individuals at each stage of the study—e.g., numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (e.g., demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) *Cohort study*—Summarise follow-up time (e.g., average and total amount)
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time *Case-control study*—Report numbers in each exposure category, or summary measures of exposure *Cross-sectional study*—Report numbers of outcome events or summary measures
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses
DISCUSSION		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
OTHER INFORMATION		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give such information separately for cases and controls in case-control studies, and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.
Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of *PLoS Medicine* at http://www.plosmedicine.org/, *Annals of Internal Medicine* at http://www.annals.org/, and *Epidemiology* at http://www.epidem.com/). Separate versions of the checklist for cohort, case-control, and cross-sectional studies are available on the STROBE Web site at http://www.strobe-statement.org/.
doi:10.1371/journal.pmed.0040297.t001

Appendix C

Quality rating checklist

		Yes OR No OR Can’t tell
Study design	1. Has the study design been reported?	
Study objectives	2. Have the aims and objectives of the study been reported?	
Methods of selecting study participants/cases (and controls)	3. Has the location of the study been described?	
	4. Have relevant dates including periods of recruitment/data collection been reported?	
	5. Are the cases of suicide within the study period representative of the target population or area (e.g. those who have previously received mental health inpatient treatment)?	
	6. Has the inclusion and/or exclusion criteria been stated?	
	7. Have the number of suicides excluded from the study been reported?	
	8. Has a power calculation been used to justify the sample size?	
	9. Have the sources and methods of selecting cases (and controls if applicable) been described?	
	10. Were unique patient identity numbers such as social security numbers used to identify cases?	
	11. Has the study been controlled and if so has the matching criteria and number of controls per case been reported?	
Methods for measuring variables of interest (e.g. details of psychiatric admission, diagnosis, demographics) and outcome, suicide)	12. Has the method for extracting the variables of interest been described?	
	13. Has a definition been provided for all the variables of interest (including suicide) and any categorisations that have been applied?	
	14. Has the study used the ICD or DSM to define suicide cases?	
	15. Are the definitions or classifications of other variables of interest (excluding suicide) based on a standardized definition (e.g. DSM, ICD, definition has been adopted in previous studies which have been referenced)?	
Design-specific sources of bias	16. Was clinical data collected prospectively?	
	17. Does the study design or methodology avoid or minimise error due to systematic recall bias?	
	18. Does the study design or methodology avoid or minimise error due to misclassification of variables (e.g. psychiatric diagnoses, suicide), changes in classification of variables over time or inaccuracy in data recording?	
	19. Were researchers examining/obtaining the information or clinicians providing information blind to the suicide outcome?	

	20. Where information was: - Obtained via medical records, was inter-rater reliability or test-retest reliability reported? - Collected via interviews or questionnaires, were multiple informants approached? - Collected via electronic databases, was the information available sufficiently exhaustive to meet study aims/identify potential confounders?	
Methods to control confounding	21. Have potential confounders been defined?	
	22. Has the inclusion of potential confounders been justified?	
	23. Have methods been taken to control confounding, by study design and/or analytical methods?	
	24. Have confounder-adjusted estimates and their precision (e.g. confidence intervals) been reported?	
Statistical methods (excluding control of confounding)	25. Was the sample on which statistical methods were applied large enough for sufficiently precise estimates (referring to the power calculation if reported)?	
	26. Do the statistical methods chosen enable the aims and objectives of the study to be met and/or are they suitable for the chosen study design?	
External validity	27. Was the study located in the UK?	
	28. Was the generalisability of the study results discussed?	
Conflict of interest	29. Is there a declaration of conflict of interest?	
	30. Are sources of funding identified?	

Appendix D

Notes to aid completion of quality rating tool

- In general, rate items ‘can’t tell’ if there is lack of clarity in what has been reported or the way something has been reported.
- Q. 5 – rate as ‘yes’ if an attempt has been made to identify all suicides after discharge in a certain area or region.
- Q. 11 – rate as ‘yes’ only if study is controlled AND reported matching criteria AND number of controls per case.
- Q.13 – if psychiatric diagnoses are included as a variable of interest, only rate as ‘yes’ if DSM or ICD have been used to classify diagnoses. Consider other variables of interest – where necessary have authors referred to previous literature when classifying, categorising or determining proxy measures? If so rate as ‘yes’, if not rate as ‘no.’
- Q. 16 – rate as ‘yes’ if data was collected via electronic databases, as this data was recorded at the time of admission and/or discharge rather than retrospectively post-suicide. Rate as ‘no’ if data was collected via interviews/questionnaires or medical records. Although medical records may have recorded data prospectively, there is more subjectivity in the collection of this data so it is not deemed to be purely prospective data.
- Q.17 – rate as ‘yes’ if authors have discussed attempts to minimise recall bias.
- Q.18 – rate as ‘yes’ if authors have provided a valid argument to indicate that error due to misclassification or inaccuracy would be minimal. For example, due to use of strict definitions.
- Q. 19 – blinding in this case relates to whether or not researchers were blind to outcome when the information has been collected for the purposes of the current research rather than whether those recording the data were blind to outcome.
- Q. 20 – where information was collected via electronic databases- ‘sufficiently exhaustive’ relates to whether or not there were key clinical features associated with post-discharge suicide which could not be identified as the data was not available.
- Q.25 – Rate as ‘yes’ if national data has been used and authors have indicated that the sample was large enough, otherwise rate as ‘no’ or ‘can’t tell’ if no power calculation has been reported.
- Q.26 – Rate as ‘can’t tell’ if study design has not been reported.

Appendix E

Summary of quality assessment results

	Hoffman (1987)	Hunt (2009)	Kan (2007)	King (2001)	Lee (2009)	Lin (2008)	McKenzie (2001)
Study design reported	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Aims and objectives reported	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Study location described	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Relevant dates reported	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Cases of suicide representative of the target population/area	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Inclusion and/or exclusion criteria stated	Yes	Yes	Yes	Yes	Yes	Yes	No
Number of suicides excluded reported	No	No	No	Yes	No	No	No
Power calculation been used	No	Yes	Yes	Yes	No	No	No
Sources and methods of selecting cases described	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Unique patient identity numbers used to identify cases	No	No	Yes	No	No	No	No
Study controlled and matching criteria reported	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Method for extracting the variables of interest described	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Definition provided for all the variables of interest	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes
Study used the ICD or DSM to define suicide cases	Can't tell	Can't tell	Yes	Yes	Yes	Yes	Can't tell
Definitions based on a standardized definition	Yes	Can't tell	Yes	No	Yes	Yes	Can't tell
Clinical data collected prospectively	No	No	No	No	Yes	Yes	No
Avoids or minimises error due to systematic recall bias	Yes	No	Yes	Yes	Yes	Yes	Yes
Avoids or minimises error due to misclassification of variables	Can't tell	No	Yes	Yes	No	No	Yes
Blind to the suicide outcome	No	No	No	No	Yes	Yes	No
Collection of clinical data – reliability reported, multiple informants approached or electronic data was sufficiently exhaustive	Yes	Can't tell	Yes	Yes	No	No	No
Potential confounders defined	No	No	Yes	Yes	No	Yes	No
Inclusion of potential confounders justified	No	No	No	Yes	No	Yes	No
Methods taken to control confounding	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Confounder-adjusted estimates and their precision reported	No	Yes	No	Yes	Yes	Yes	No
Sample is large enough	Can't tell	Yes	Can't tell	No	Can't tell	No	Can't tell
Statistical methods chosen are suitable	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Study located in the UK	No	Yes	No	Yes	No	No	Yes
Generalisability of the study results discussed	No	Yes	No	No	Yes	Yes	No
Declaration of conflict of interest	No	Yes	No	No	No	Yes	No
Sources of funding identified	No	Yes	No	Yes	Yes	Yes	No
Total number of 'yes' scores	**14**	**19**	**20**	**23**	**20**	**23**	**14**

	Modestin (1992)	Pirkola (2005)	Pirkola (2007)	Pokorny (1976)	Tseng (2010)	Yim (2004)
Study design reported	Yes	Yes	Yes	Yes	Yes	Yes
Aims and objectives reported	Yes	Yes	Yes	Yes	Yes	Yes
Study location described	No	Yes	Yes	Yes	Yes	Yes
Relevant dates reported	Yes	Yes	Yes	Yes	Yes	Yes
Cases of suicide representative of the target population/area	Can’t tell	Yes	Yes	Can’t tell	Yes	Yes
Inclusion and/or exclusion criteria stated	No	No	No	No	Yes	Yes
Number of suicides excluded reported	No	No	No	No	No	Yes
Power calculation been used	No	No	No	No	No	No
Sources and methods of selecting cases described	Yes	Yes	Yes	Yes	Yes	Yes
Unique patient identity numbers used to identify cases	No	Yes	Yes	No	Can’t tell	Yes
Study controlled and matching criteria reported	Yes	No	No	Yes	No	Yes
Method for extracting the variables of interest described	No	Yes	Yes	Yes	Yes	Yes
Definition provided for all the variables of interest	Can’t tell	Can’t tell	Yes	No	Yes	Yes
Study used the ICD or DSM to define suicide cases	Can’t tell	Yes	Yes	Can’t tell	Yes	No
Definitions based on a standardized definition	Can’t tell	Yes	Yes	Yes	Yes	No
Clinical data collected prospectively	No	Yes	Yes	Yes	Yes	Yes
Avoids or minimises error due to systematic recall bias	No	No	Yes	No	Yes	No
Avoids or minimises error due to misclassification of variables	Can’t tell	Yes	Yes	Can’t tell	No	No
Blind to the suicide outcome	No	Yes	No	No	Yes	No
Collection of clinical data – reliability reported, multiple informants approached or electronic data was sufficiently exhaustive	No	No	Yes	No	Can’t tell	Yes
Potential confounders defined	Yes	Yes	No	No	Yes	Yes
Inclusion of potential confounders justified	No	No	Yes	No	No	No
Methods taken to control confounding	Yes	Yes	Yes	Yes	Yes	Yes
Confounder-adjusted estimates and their precision reported	No	Yes	Yes	No	Yes	Yes
Sample is large enough	Can’t tell	Can’t tell	Can’t tell	Can’t tell	Can’t tell	Can’t tell
Statistical methods chosen are suitable	Yes	No	Yes	Yes	Yes	Yes
Study located in the UK	No	Yes	No	No	No	No
Generalisability of the study results discussed	No	No	No	No	Yes	Yes
Declaration of conflict of interest	No	Yes	Yes	No	No	No
Sources of funding identified	No	Yes	Yes	No	No	No
Total number of ‘yes’ scores	**8**	**19**	**21**	**11**	**19**	**19**

Appendix F

Characteristics of included studies

Author, publication year, aims	Location, time, period	Design	Suicide cases	Comparison group	Clinical data	Statistical analysis technique	Results
Hoffman et al. (1987). To identify the differences at the time of discharge between those who go on to commit suicide during the year after discharge and those who do not.	Psychiatric University Clinic of Berne, 1971-1981.	Retrospective analysis of clinical case records	**Characteristics:** Patients who committed suicide during the study period and were discharged from psychiatric inpatient treatment within a year of their death. **Identification:** Police files, compared names of those receiving psychiatric treatment with patient archives held at hospital. **Number:** 53 **Age:** Not reported **Definition:** Not reported **Time since discharge:** Suicide within a year **Diagnosis:** Coded according to the ICD **Exclusion/inclusion criteria:** Excluded those committing suicide outside study period	**Characteristics:** Group 1: patients who were discharged from psychiatric inpatient care at the same time and were not subsequently admitted. Group 2: discharged psychiatric inpatients **Identification:** Patient archives **Number:** 53 in each group **Matching criteria:** Group 1: date of discharge. Group 2: sex, date of discharge	**Ascertainment:** Medical records, some level of blindness (not for comparison group 2) **Data collected:** Demographic variables, diagnosis, suicidal behaviour, social circumstances, forensic history.	Descriptive stats and chi-square statistic reported	No significant differences were found between suicides and controls with regard to most sociodemographic and clinical variables investigated. Significantly more suicides than controls had attempted suicide in the past (C1 vs. S, χ2 = 7.44, p= <0.001, C2 vs. S, χ2=7.44, p=<0.01). Attempters in the suicide group attempted suicide more frequently (C1 vs. S, χ2 = 5.63, p= <0.02, C2 vs. S, χ2=6.84, p=<0.01), their suicide attempts were more serious (C1 vs. S, χ2 = 9.92, p= <0.02, C2 vs. S, χ2=11.37, p=<0.01). No differences between the groups in terms of referral to follow-up care, no differences as to the living conditions the patient was discharged to.

Author, publication year, aims	Location, time, period	Design	Suicide cases	Comparison group	Clinical data	Statistical analysis technique	Results
Hunt et al. (2009). To compare cases of suicide with surviving post-discharge controls to identify clinical and psychosocial risk factors, including variation in aftercare received, for suicide within three months of discharge.	England, 2000-2001	Case-control study	**Characteristics:** Consecutive series of individuals who were discharged from psychiatric inpatient care in the study period and died by suicide within three months. **Identification:** Office for National Statistics **Number:** 238 **Age:** 16-65 years **Definition:** Verdict of suicide or open suicide at coroner's inquest **Time since discharge:** Suicide within three months of discharge **Diagnosis:** Not specified **Exclusion/inclusion criteria:** Suicides over 65 years	**Characteristics:** Surviving controls who had been a psychiatric inpatient **Identification:** Nationwide Clearing Service Database, collects anonymized data on all psychiatric NHS inpatient admissions in England **Number:** 238 **Matching criteria:** Having been in inpatient care, discharged on the same day as the corresponding case.	**Ascertainment:** Psychiatrist completed a questionnaire following suicide, adapted for control cases **Data collected:** Sociodemographic characteristics, clinical history, details of the suicide, aspects of care and details of the preceding inpatient admission and discharge	Pearson's chi-squared test (suicide <1 month post discharge compared to 1-3 months post discharge)	Those who died within the first month of discharge were more likely to be male, χ^2 (df?, *N*=102) = 3.88, *p*= 0.05, with a history of violence and self-harm, χ^2 (df?, *N*=102) = 4.31, *p*= 0.04 , and to have had contact with services within a week of death , χ^2 (df?, *N*=102) = 10.34, *p*= 0.001 compared with later suicides.
						Conditional logistic regression	Eight independent predictors of suicide: male gender (OR = 2.2, 95% CI = 1.3-3.8), history of self-harm harm (OR = 3.2, 95% CI = 1.9-5.5), primary diagnosis of affective disorder (OR = 2.3, 95% CI = 1.3-3.9), psychiatric co-morbidity, suicidal ideation, recent last contact (OR = 2.2, 95% CI = 1.3-3.8), patient-initiated discharge (OR = 2.5, 95% CI = 1.4-4.5) and missed last appointment with services (OR = 2.1, 95% CI = 1.1-3.9). The prevalence of multiple risk factors was high.

Author, publication year, aims	Location, time, period	Design	Suicide cases	Comparison group	Clinical data	Statistical analysis technique	Results
Kan et al. (2007). To describe the characteristics and examine risk factors of suicide within 60 days of discharge.	Hong Kong, China, 1997-1999.	Case-control study	**Characteristics:** Patients discharged in the study period from all psychiatric hospitals in Hong Kong who killed themselves within 60 days of discharge. **Identification:** Data from the psychiatric hospital database was cross-linked with the data of suicide and undetermined deaths using personal identifiers (name, sex, age, identity card number) **Number:** 98 (medical records of 1 was not found, analysis based on 97) **Age:** Not reported **Definition:** Coronor's verdicts of suicide and undetermined death, coded according to ICD-9 (E950-959 and E980-989) **Time since discharge:** Suicide within 60 days **Diagnosis:** Categorised into five groups, based on clinical diagnosis using ICD-10. **Exclusion/inclusion criteria:** None reported	**Characteristics:** Surviving patients discharged in the same three-year period **Identification:** Electronic database of the psychiatric hospital **Number:** 97 **Matching criteria:** Age, sex, diagnosis, date of discharge and hospital attended.	**Ascertainment:** Examination of medical records, using The Questionnaire for Hong Kong Psychiatric Patients' Suicide, based on the Wessex Recent Inpatient Suicide Study (King et al., 2001), rated separately by two raters, only 1 variable had poor reliability **Data collected:** Demographics, psychiatric and medical history, treatment provided, psychiatric symptoms, social circumstances.	Descriptive statistics	The most common diagnosis and suicide method was schizophrenia and falling from a height, respectively.
						Conditional logistic regression	Risk factors for suicide were; previous DSH (OR = 2.3, 95% CI = 1.07-5.05), admission for DSH (OR = 3.2, 95% CI = 1.3-7.8) compulsory admission (OR = 3.1, 95% CI = 1.1-8.7), living alone (OR = 5.8, 95% CI = 1.4-23), work stresses (OR = 5.4, 95% CI = 1.5-1.8) and being out of contact (OR = 7.9, 95% CI = 1.87-33).
						Sensitivity, specificity and ROC analysis	As a screening tool, the number of risk factors rendered better sensitivity than any individual risk factor. The risk of suicide increased with exposure to multiple risk factors; in the studied population (cases and controls), 78.9% of those with 3 risk factors died by suicide.

Author, publication year, aims	Location, time, period	Design	Suicide cases	Comparison group	Clinical data	Statistical analysis technique	Results
King et al. (2001). To identify social, clinical and health-care delivery factors in recently discharged patients.	Wessex, UK, 1988-1997.	Case-control study	**Characteristics:** All those residents of Wessex who were discharged in the study period from psychiatric hospital and committed suicide within a year. **Identification:** Official mortality files and coroner's registers to identify suicide cases who died within a year of discharge from psychiatric inpatient treatment **Number:** 234 (287 identified, 53 case notes were untraceable) **Age:** Not reported **Definition:** Suicide or open verdict based on ICD-9 codes (E950-959 and E980-989) **Time since discharge:** Suicide within one year **Diagnosis:** Four categories – schizophrenia and schizophrenia-like disorders, non-psychotic affective disorders and 'residual' diagnoses, unclear of the ICD codes used to make up each category. **Exclusion/inclusion criteria:** Suicides coded as E9888 – 'injury by other specified means, undetermined whether accidentally or purposely inflicted'. Non-Wessex admissions (*n* = 11) excluded	**Characteristics:** Patients who received inpatient treatment and survived. **Identification:** Unclear **Number:** 431 (1:1.84, power calculation reported) **Matching criteria:** Age, sex, diagnosis, date of admission period	**Ascertainment:** Examination of medical records by a psychiatrist and recorded on a specifically designed pro forma, test-retest exercise undertaken. **Data collected:** Demographic information, psychiatric history, medical history, index admission information, discharge data, treatment at admission, last contact, status of arranged follow-up, continuity of contact, changes in personnel after discharge	Multiple conditional logistic regression	Increased risk factors were; previous DSH (OR = 4.09, 95% CI = 2.58-6.48), suicidal ideation precipitating admission (OR = 1.93, 95% CI = 1.22-3.06), hopelessness (OR = 1.82, 95% CI = 1.04-3.19), admission under different consultant (OR = 1.56, 95%, CI = 1.01-2.41), onset of relationship difficulties (OR = 4.89, 95% CI = 1.13-21.15), loss of job (OR = 7.88, 95% CI = 2.09-29.71), inpatient DSH (OR = 2.57, 95% CI = 1.00-6.62), unplanned discharge (OR = 2.73, 95% CI = 1.77-4.22), significant care professional left/on leave (OR = 16.82, 95% CI = 3.54-79.80). Reduced risk factors were; shared accommodation (OR = 0.28, 95% CI = 0.10-0.77), delusions at admission (OR = 0.48, 95% CI = 0.26-0.86), misuse of non-prescribed substances (OR = 0.39, 95% CI = 0.17-0.88), continuity of contact (OR = 0.63, 95% CI = 0.40-1.00).

Author, publication year, aims	Location, time, period	Design	Suicide cases	Comparison group	Clinical data	Statistical analysis technique	Results
Lee et al. (2009). To identify the risk factors for suicide among schizophrenia patients in the three month post-discharge period.	Taiwan, China, 2002-2004.	Case-control study	**Characteristics:** Patients discharged in the study period from psychiatric inpatient care in Taiwan with a principal diagnosis of schizophrenia who committed suicide within 90 days of discharge **Identification:** Cause of death file provided by the Taiwanese Department of Health linked with the National Health Insurance Research Database. **Number:** 87 **Age:** Not reported **Definition:** ICD-9 codes E950-E959. **Time since discharge:** Suicide within 90 days **Diagnosis:** Schizophrenia **Exclusion/inclusion:** Only voluntary admissions selected	**Characteristics:** All surviving patients discharged from psychiatric inpatient care for the treatment of schizophrenia in the same period **Identification:** The National Health Insurance Research Database. **Number:** 348 (1:4) **Matching criteria:** Age, sex and date of discharge	**Ascertainment:** Electronic database – the National Health Insurance Research Database. **Data collected:** Sociodemographics, clinical features, psychiatrist characteristics	Pearson's chi-squared test (differences between the cases and controls)	Chi-squared statistic not reported in tables or text. Description states that there were significant differences between cases and controls in terms of length of stay for the index hospitalization, the number of admissions in the year prior to index admission, unplanned discharge and psychiatrist gender and age.
						Cox proportional hazard regression	Risk factors related to having not had a psychiatric admission in the year prior to the index admission, length of stay and being treated by a male psychiatrist who was over 44 years old, however there was some lack of clarity in reporting of results.
Lin et al. (2008). To explore risk factors associated with depressed patients who committed suicide within 3 months of discharge	Taiwan, China, 2002-2004	Case-control study	**Characteristics:** Patients discharged in the study period from psychiatric departments of hospitals with a principal diagnosis of depression who committed suicide within 90 days of discharge. **Identification:** Cause of death file provided by the Taiwanese Department of Health linked with the National Health Insurance Research Database. **Number:** 85 **Age:** Not reported **Definition:** ICD-9 codes E950-E959. **Time since discharge:** Suicide within 90 days **Diagnosis:** Major depressive disorder (ICD-9 codes 296.2, 296.3, 300.4 and 311) **Exclusion/inclusion:** Excluded patients who had a diagnosis history of bipolar disorder, schizophrenia, other psychoses, cognitive impairment or dementia within the two years prior to the index hospitalization.	**Characteristics:** All surviving patients discharged from psychiatric departments of hospitals with a principal diagnosis of depression during the study period (same exclusion criteria applied). **Identification:** The National Health Insurance Research Database. **Number:** 425 (1:5) **Matching criteria:** Age, sex and date of discharge	**Ascertainment:** Electronic database – the National Health Insurance Research Database. **Data collected:** Hospital characteristics, psychiatrist characteristics, patients characteristics at index hospitalization.	Pearson's chi-squared test (differences between the cases and controls)	Significant differences between cases and controls in terms of patient-initiated discharge χ2 (df?, *N*=85) = 8.539, *p*= 0.004, and hospital type (χ2 (df?, *N*=85) = 9.671, p= 0.008.
						Cox proportional hazard regression	The adjusted hazard of committing suicide after hospital discharge for patients who discharged themselves was 2.85 times (95% CI = 1.387-5.856) greater than for those who were discharged with doctors' approval. The hazard of committing suicide among patients discharged from medical centres was 3.38 times (95% CI = 1.421-8.055) that for their counterparts discharged from regional hospitals.

Author, publication year, aims	Location, time, period	Design	Suicide cases	Comparison group	Clinical data	Statistical analysis technique	Results
McKenzie et al. (2001). To identify what proportion of suicides have had contact with mental health services and the type of contact and to identify risk factors associated with early suicides.	Bradford, UK, 1981-1990	Case-control study	**Characteristics:** Those who had been admitted to either of the two psychiatric hospitals in Bradford within the study period **Identification:** Inquest records to identify verdicts of death by suicide or undetermined injury ('open verdict') over a 10 year period, unclear how cases were identified as having been inpatients. **Number:** 257 (20 within three months of discharge) **Age:** Not reported **Definition:** Suicide or undetermined injury (unclear if ICD codes were used) **Time since discharge:** No timing determined during sampling, for analysis divided into early suicide (within three months of discharge) and late suicide (between three months of discharge and time of case note review) **Diagnosis:** None specified, at data collection six categories were devised, unclear if ICD had been used to code. **Exclusion/inclusion:** None reported.	**Characteristics:** Surviving inpatients **Identification:** Selected previous (to the case) discharged inpatients (unclear from where or how) on whom there was no record of a suicide or undetermined injury **Number:** 77 **Matching criteria:** Age at discharge (within 5 years), gender and hospital of admission	**Ascertainment:** Hospital records from the last admission (cases) or index admission (controls) **Data collected:** Sociodemographic characteristics, medical history, variables concerning last admission, follow-up arrangements	Univariate analysis (comparing early suicides with controls and late suicides)	Four variables differedt significantly between early suicide and controls; previous history of DSH, diagnosis of mood disorder, suicide attempt or communication of suicidal intent during the last hospital admission and longer medical records. Only a previous history of DSH significantly discriminated between early and late suicides.
						Stepwise conditional logistic regression	Only written summary and p values provided, unclear if adjusted for confounding variables. Analysis revealed three significant variables predicting early versus no suicide: past history of DSH (*p*=<0.00001), diagnosis of mood disorder (*p*=< 0.01), and longer medical entries in the case notes (*p*=<0.01). A past history of DSH (*p*=<0.01) predicted early as against late suicides, with a diagnosis of mood disorder nearly reaching significance (*p*=0.058).
Modestin et al. (1992). To examine modalities of the treatment received by cases and controls to explore whether suicide could be reduced by improving the therapy.	Switzerland, 1976-1986.	Retrospective case-control study (although not specified)	**Characteristics:** All those who were discharged from a particular psychiatric hospital in Switzerland in the study period and committed suicide within a year. **Identification:** Police files **Number:** 64 (75 identified, 11 case notes were not sufficiently detailed or a suitable control patient could not be identified) **Definition:** Not reported **Time since discharge:** Suicide within one year **Diagnosis:** None specified **Exclusion/inclusion:** None reported	**Characteristics:** Those who received inpatient treatment at the same time as cases but did not commit suicide within a year of discharge. **Identification:** Hospital register **Number:** 64 **Matching criteria:** Same year of discharge, same sex, similar age (± 5 years), principal diagnosis.	**Ascertainment:** Hospital charts, records from therapists for post-discharge outpatient treatment, therapists interviewed on the phone. **Data collected:** Sociodemographic and clinical data, treatment patients received, using a self-prepared standardized sheet.	Descriptive stats and chi-square test	One third of patients in both groups were no longer in treatment at the time of suicide, or corresponding point in time for cases. At that time, a significantly higher proportion of controls were receiving psychopharmacotherapy ($\chi2 = 8.24$, p<0.01) and a significantly higher proportion were receiving lithium

Author, publication year, aims	Location, time, period	Design	Suicide cases	Comparison group	Clinical data	Statistical analysis technique	Results
Pirkola et al. (2005). To explore the characteristics of those who commit suicide within a week of discharge	Finland, 1980-2001.	Nationwide register study	**Characteristics:** Those committing suicide in the study period who had been psychiatric inpatients **Identification:** National Cause of Death Register, personal identification codes of subjects were linked to the Finnish Hospital Discharge Register and the Finnish Health Care Register. **Number:** 8 096 in total, 1 407 committed suicide within a week post-discharge **Age:** Not reported **Definition:** Not reported **Time since discharge:** No timing determined during sampling, in analysis compared those committing suicide within a week post-discharge with later suicides. **Diagnosis:** Coded using ICD, the classification changed twice across study period so primary discharge diagnoses were converted to ICD-10. **Exclusion/inclusion:** None reported	**Characteristics:** Previously hospitalised patients who committed suicide later than a week post-discharge **Identification:** National Cause of Death Register, personal identification codes of subjects were linked to the Finnish Hospital Discharge Register and the Finnish Health Care Register. **Number:** 6 689 **Matching criteria:** N/A	**Ascertainment:** The Finnish Hospital Discharge Register, the Finnish Health Care Register and registers of statistics. **Data collected:** Data on the psychiatric hospitalizations preceding suicide, discharge diagnosis, involuntary treatment acts during the last hospitalization (available 1995 onwards) sociodemographic variables, Global Assessment Scale (registered 1995 onwards)	Bivariate analysis – chi-square test and two-tailed t-test	Compared to other previously hospitalised suicide victims, those committing suicide within a week of discharge were more often female, unmarried, used drowning, jumping or hanging as suicide methods and were diagnosed with schizophrenia or affective disorders. Chi-square and t-test statistics not reported.
						Logistic regression	Committing suicide within a week of discharge was associated with; being female (OR = 2.30, 95% CI = 2.10-2.58), being unmarried (OR = 1.29, 95% CI = 1.12-1.49), having a higher grade of education (OR = 1.57, 95% CI = 1.34-1.83), being retired (OR = 2.54, 95% CI = 2.11-3.06), drowning (OR = 3.38, 95% CI = 2.75-4.16), diagnosed with affective disorders (OR = 2.3, 95% CI = 1.68-3.08) or schizophrenia and similar psychoses (OR = 2.3, 95% CI = 1.67-3.07).

Author, publication year, aims	Location, time, period	Design	Suicide cases	Comparison group	Clinical data	Statistical analysis technique	Results
Pirkola et al. (2007). Analyse trends in suicides occurring in psychiatric hospitalization following deinstitutionalisation, downsizing of inpatient care and decentralisation.	Finland, 1985-1991 and 1995-2001.	Nationwide register study	**Characteristics:** Those committing suicide during the study period, within a year/a week of discharge from psychiatric inpatient wards. **Identification:** National Register for Causes of Death. Personal identification codes of cases were linked to the Finnish Hospital Discharge Register, including data on inpatient treatment. **Number:** 1985-1991 *n*=1 981 suicides hospitalised in previous year, 1995-2001 *n* = 1 865 suicides hospitalised in previous year **Age:** Not reported **Definition:** Any suicide, according to the ICD, occurring within a year of discharge from psychiatric ward, unclear which ICD codes were included. **Time since discharge:** Suicide within a year of discharge **Diagnosis:** Discharge diagnoses from psychiatric treatment periods were all converted to ICD-10 codes. **Exclusion/inclusion:** Included suicides occurring on day of discharge.	**Characteristics: (i)** Suicides in the two time periods who did not receive psychiatric inpatient care in the year before their death. **(ii)** Discharged patients in the two time periods **Identification:** National Register for Causes of Death and Finnish Hospital Discharge Register. **Number: (i)** 1985-1991 *n*=7 738, 1995-2001 *n*=6 896. **(ii)** 1985-1991 *n*=163 236, 1995-2001 *n*=191 764. **Matching criteria:** N/A	**Ascertainment:** Registers of Statistics, Finland. **Data collected:** Sociodemographic variables	For bivariate analysis used chi-square test and two-tailed *t* test.	In both time periods, those committing suicide who had been hospitalised in preceding year were more likely to be female, retired, have a higher level of education and to be unmarried or divorced. Chi-square and t-test statistics not reported.
						Logistic regression models	Increased risk factors for suicide within a year of discharge in both time periods were being female (1985-1991, OR = 1.78, 95% CI=1.59-2.00; 1995-2001, OR=1.48, 95% CI = 1.32-1.67), being retired (1985-1991, OR=2.04, 95% CI=1.72-2.41; 1995-2001, OR=2.45, 95% CI=2.11-2.85), having a higher level of education (1985-1991, OR=1.7, 95% CI=1.43-2.03; 1995-2001, OR=1.49, 95% CI=1.27-1.75).
						Linear regression to analyse time trends	The risk of suicide was greater in 1985-1991 than in 1995-2001 for both one week after discharge (RR = 1.50, 95% CI = 1.38-1.62) and one year after discharge (RR = 1.25, 95% CI = 1.19-1.30).

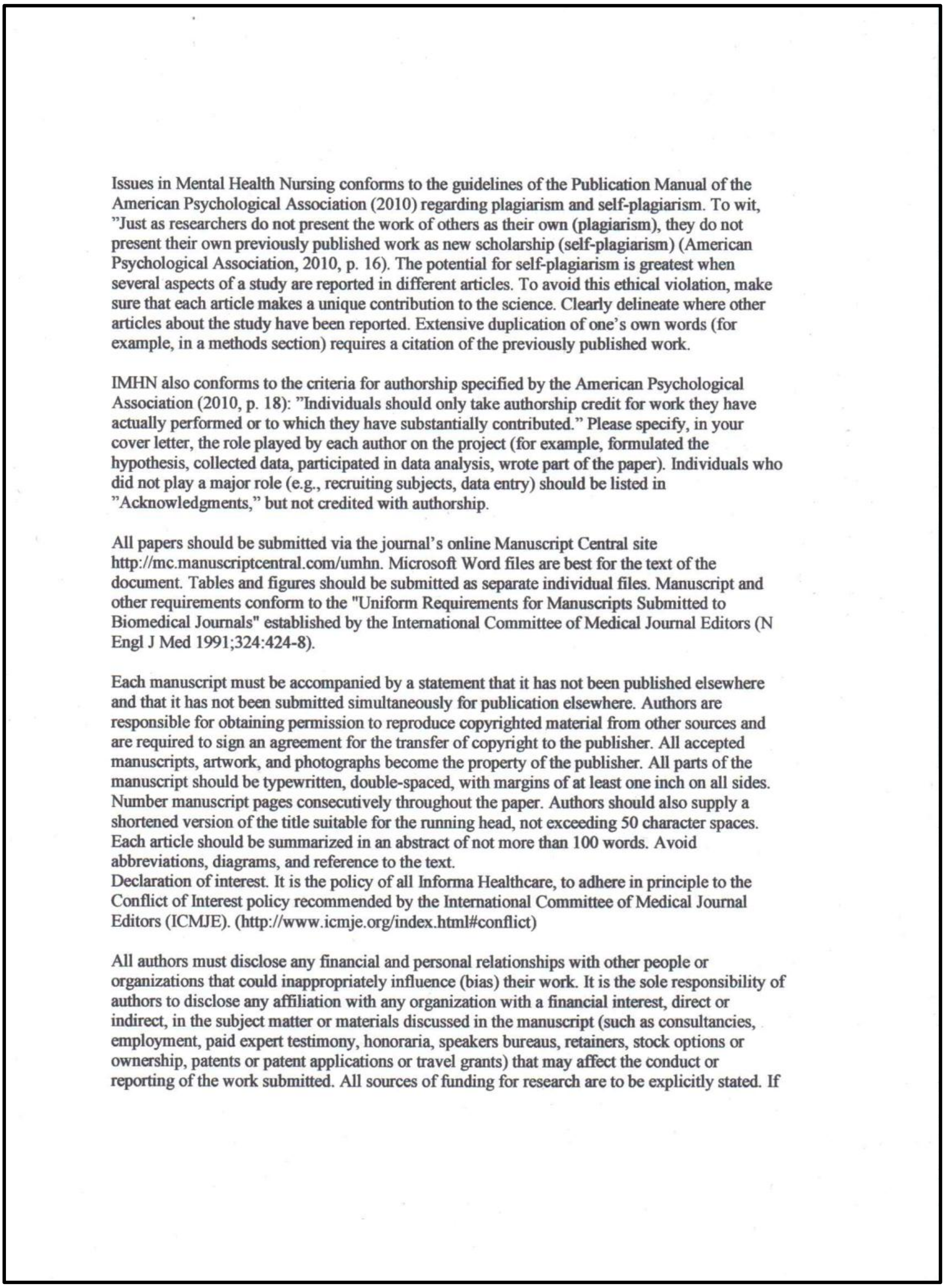
Author, publication year, aims	Location, time, period	Design	Suicide cases	Comparison group	Clinical data	Statistical analysis technique	Results
Pokorny et al. (1976). To test the interaction between defenselessness and adverse life events in completed suicide.	Texas, 1972-1974.	Case-control (although not specified)	**Characteristics:** VA psychiatric inpatients **Identification:** Continual monitoring of newspaper obituary column, state health department monthly list of deaths among ex-serviceman, records of nearby Veterans Administration hospitals and word of mouth to hospital staff **Number:** 19 (20 in total identified, 1 case of suicide was not within a year of discharge) **Age:** Mean age 38 **Definition:** Not reported **Time since discharge:** 19 within one year, 1 within 2 ½ years since discharge **Diagnosis:** Not reported **Exclusion/inclusion:** None reported	**Characteristics:** Patients who were discharged from inpatient treatment during the study period and survived. **Identification:** Not reported **Number:** 20 **Matching criteria:** Age, race, time at risk in the community.	**Ascertainment:** Defenselessnes defined in terms of scores derived from the extended Brief Psychiatric Rating Scale. To rate adverse life events used the Social Readjustment Rating Scale. **Data collected:** By psychiatrists and informants after suicide occurred, score for defenselessness and score for adverse life events.	Chi-squared test and Fisher's exact test.	Completed suicides were significantly more likely to both have had high defenselessness scores at the time of hospitalisation and to have experienced adverse life events after discharge ($\chi2 = 7.0$, $p<0.01$). Neither circumstance in the absence of the other was predictive.

Author, publication year, aims	Location, time, period	Design	Suicide cases	Comparison group	Clinical data	Statistical analysis technique	Results
Tseng et al. (2010). To identify the characteristics associated with early suicide of those patients discharged from psychiatric wards in Taiwan.	Taiwan, China, 2000-2004.	Retrospective (no other details reported)	**Characteristics:** People who committed suicide during the study period, within one year of discharge from psychiatric wards. **Identification:** Nationwide mortality database linked to the Inpatient Medical Claims database, which contains all inpatient claims for insured patients. **Number:** 672 suicides within one year of discharge, 197 within one month, 86 within one week. **Age:** None reported **Definition:** Identified all deaths according to ICD-9 codes E950-E959 **Time since discharge:** Suicides within a year/month/week **Diagnosis:** Diagnoses coded according to ICD-9 **Exclusion/inclusion:** Excluded patients whose admission and discharge dates were the same and patients whose suicide and discharge dates were the same.	Study compared those who committed suicide within a year with those who committed suicide within 1 week and 1 month **Characteristics:** N/A **Identification:** N/A **Number:** N/A **Matching criteria:** N/A	**Ascertainment:** Death records, inpatient medical claims database. **Data collected:** Demographic variables, variables related to use of inpatient care, diagnosis	Bivariate analysis using chi-square tests	Patients committing suicide within 1 week of discharge compared to those committing suicide later (63.95% vs. 76.28%, respectively) were less likely to be those with disease duration of more than 12 months (*p*=.0202). No other variables were significant, chi square statistic not reported.
						Logistic regression	Increased odds of committing suicide within a week of discharge were found to be those with a diagnosis of schizophrenia (OR=2.098, 95% CI=1.110-3.962). Patients with a disease duration of over 12 months were associated with decreased odds of committing suicide within 1 week of discharge (OR=0.574, 95% CI=0.353-0.934). Schizophrenia (OR=1.585, 95% CI=1.005-2.500) and comorbidity of cancer (OR=2.508, 95% CI=1.186-5.302) were positively associated with committing suicide within 1 month of discharge. Disease duration of more than 12 months was negatively correlated with suicide occurring within 1 month of discharge (OR=0.576, 95% CI=0.397-0.835).
						Kaplan-Meier analysis	Patients with comorbidity of cancer had a lower survival rate than those without cancer, but only among women (logrank test=2.94, *df*=1, *p*=0.0864; Wilcoxon test=5.2478, *df*=1, *p*=0.022). This difference remained significant until about 200 days after discharge from psychiatric inpatient care. Patients with disease duration longer than 12 months had higher survival rates than those with disease duration shorter than 12 months, for both men and women, this remained significant throughout the year after discharge (data not shown).

Author, publication year, aims	Location, time, period	Design	Suicide cases	Comparison group	Clinical data	Statistical analysis technique	Results
Yim et al. (2004). To identify the risk period and the risk factors for suicide after discharge from inpatient psychiatric treatment, also included the nature of psychiatric aftercare provided.	Regional acute general hospital, 600 psychiatric beds, Hong Kong, China, 1996-1999	Case-control study	**Characteristics:** Those discharged from psychiatric inpatient care and committing suicide during study period. **Identification:** Coroner's death reports examined, identity card number taken and matched with the computerised clinical management system to identify those with a history of a psychiatric admission. **Number:** 73 suicides during study period, 80% (68) suicides within 1 year of discharge from psychiatric care **Age:** None reported **Definition:** Death verdicts of suicide (ICD-9 E950-959) and undetermined death (ICD-9 E980-989) **Time since discharge:** Suicide within a year **Diagnosis:** Unclear if those diagnoses reported were based on ICD codes. **Exclusion/inclusion:** Patients who were not Chinese, permanent residents in Hong Kong and if they died of suicide or undetermined death during inpatient treatment or temporary leave from hospital	**Characteristics:** Those who had been discharged from psychiatric inpatient care and were still alive at the end of the study period. **Identification:** Unclear **Number:** 73, not matched for all factors **Matching criteria:** Sex, age, psychiatric diagnosis and date of discharge. Patients who had further admissions in the period between the last hospitalization and the date of death in the corresponding cases were not selected as controls.	**Ascertainment:** Death reports in the Coroner Office, inpatient psychiatric records, outpatient psychiatric records, social worker, psychologists and CPN records. **Data collected:** Used specifically designed pro forma headings: demographic factors, historical clinical factors, last psychiatric admission, last clinical contact, components of aftercare.	Descriptive statistics and univariate analysis, using chi-square and Mann-Whitney U tests.	Factors found to be significantly different between cases and controls included; being unemployed (p=0.03), past suicidal attempts (p=0.003), violent method of self-harm in the last suicidal attempt (p=0.007), mental illness in mother (p=0.07), discharge against medical advice (p=0.08), suicidal idea/attempt before admission (p=0.004), depressive symptoms before admission (p=0.003), on antidepressant (p=0.07), poor drug compliance (p=0.006), contact with psychiatrists (p=0.07), A&E (p=0.08), doctor (p=0.02) in last week. Univariate statistics not reported.
						Conditional logistic regression	In the final logistic regression model five factors best discriminated between cases and controls. These included unemployment (OR = 12.2, 95% CI = 2.1-70.4), past suicidal attempts (OR = 3.4, 95% CI = 1.2-9.6), maternal mental illness (OR = 13.4, 95% CI = 1.0-170.0) and suicidal ideation or attempt before the last admission (OR = 5.0, 95% CI = 1.4-18.0) and contact with health care services in the last week (OR = 4.0, 95% CI = 1.3-11.9).

Appendix G

Author instructions for *Issues in Mental Health Nursing*



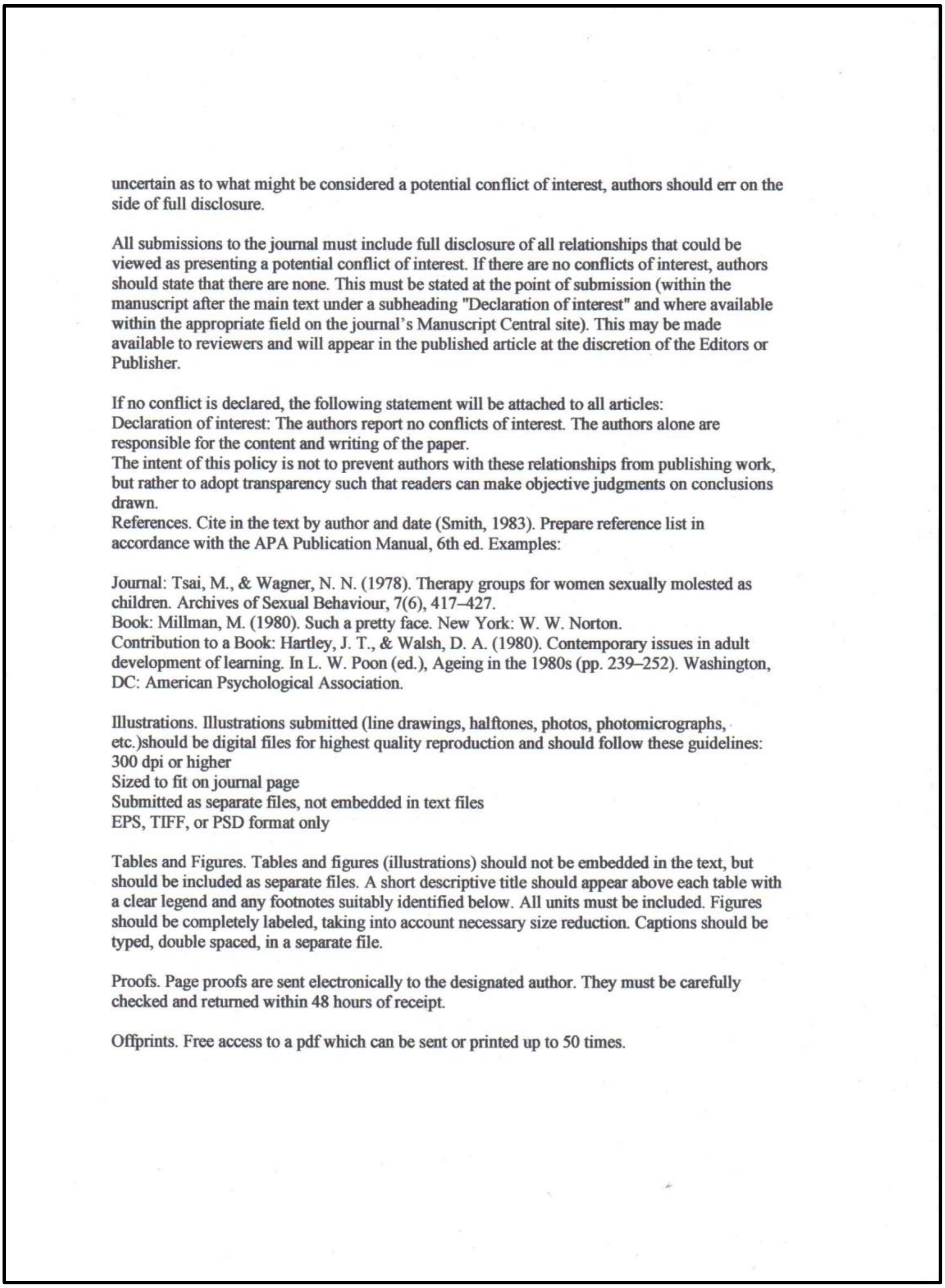
Issues in Mental Health Nursing conforms to the guidelines of the Publication Manual of the American Psychological Association (2010) regarding plagiarism and self-plagiarism. To wit, "Just as researchers do not present the work of others as their own (plagiarism), they do not present their own previously published work as new scholarship (self-plagiarism) (American Psychological Association, 2010, p. 16). The potential for self-plagiarism is greatest when several aspects of a study are reported in different articles. To avoid this ethical violation, make sure that each article makes a unique contribution to the science. Clearly delineate where other articles about the study have been reported. Extensive duplication of one's own words (for example, in a methods section) requires a citation of the previously published work.

IMHN also conforms to the criteria for authorship specified by the American Psychological Association (2010, p. 18): "Individuals should only take authorship credit for work they have actually performed or to which they have substantially contributed." Please specify, in your cover letter, the role played by each author on the project (for example, formulated the hypothesis, collected data, participated in data analysis, wrote part of the paper). Individuals who did not play a major role (e.g., recruiting subjects, data entry) should be listed in "Acknowledgments," but not credited with authorship.

All papers should be submitted via the journal's online Manuscript Central site http://mc.manuscriptcentral.com/umhn. Microsoft Word files are best for the text of the document. Tables and figures should be submitted as separate individual files. Manuscript and other requirements conform to the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals" established by the International Committee of Medical Journal Editors (N Engl J Med 1991;324:424-8).

Each manuscript must be accompanied by a statement that it has not been published elsewhere and that it has not been submitted simultaneously for publication elsewhere. Authors are responsible for obtaining permission to reproduce copyrighted material from other sources and are required to sign an agreement for the transfer of copyright to the publisher. All accepted manuscripts, artwork, and photographs become the property of the publisher. All parts of the manuscript should be typewritten, double-spaced, with margins of at least one inch on all sides. Number manuscript pages consecutively throughout the paper. Authors should also supply a shortened version of the title suitable for the running head, not exceeding 50 character spaces. Each article should be summarized in an abstract of not more than 100 words. Avoid abbreviations, diagrams, and reference to the text.
Declaration of interest. It is the policy of all Informa Healthcare, to adhere in principle to the Conflict of Interest policy recommended by the International Committee of Medical Journal Editors (ICMJE). (http://www.icmje.org/index.html#conflict)

All authors must disclose any financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work. It is the sole responsibility of authors to disclose any affiliation with any organization with a financial interest, direct or indirect, in the subject matter or materials discussed in the manuscript (such as consultancies, employment, paid expert testimony, honoraria, speakers bureaus, retainers, stock options or ownership, patents or patent applications or travel grants) that may affect the conduct or reporting of the work submitted. All sources of funding for research are to be explicitly stated. If



uncertain as to what might be considered a potential conflict of interest, authors should err on the side of full disclosure.

All submissions to the journal must include full disclosure of all relationships that could be viewed as presenting a potential conflict of interest. If there are no conflicts of interest, authors should state that there are none. This must be stated at the point of submission (within the manuscript after the main text under a subheading "Declaration of interest" and where available within the appropriate field on the journal's Manuscript Central site). This may be made available to reviewers and will appear in the published article at the discretion of the Editors or Publisher.

If no conflict is declared, the following statement will be attached to all articles:
Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.
The intent of this policy is not to prevent authors with these relationships from publishing work, but rather to adopt transparency such that readers can make objective judgments on conclusions drawn.
References. Cite in the text by author and date (Smith, 1983). Prepare reference list in accordance with the APA Publication Manual, 6th ed. Examples:

Journal: Tsai, M., & Wagner, N. N. (1978). Therapy groups for women sexually molested as children. Archives of Sexual Behaviour, 7(6), 417–427.
Book: Millman, M. (1980). Such a pretty face. New York: W. W. Norton.
Contribution to a Book: Hartley, J. T., & Walsh, D. A. (1980). Contemporary issues in adult development of learning. In L. W. Poon (ed.), Ageing in the 1980s (pp. 239–252). Washington, DC: American Psychological Association.

Illustrations. Illustrations submitted (line drawings, halftones, photos, photomicrographs, etc.)should be digital files for highest quality reproduction and should follow these guidelines:
300 dpi or higher
Sized to fit on journal page
Submitted as separate files, not embedded in text files
EPS, TIFF, or PSD format only

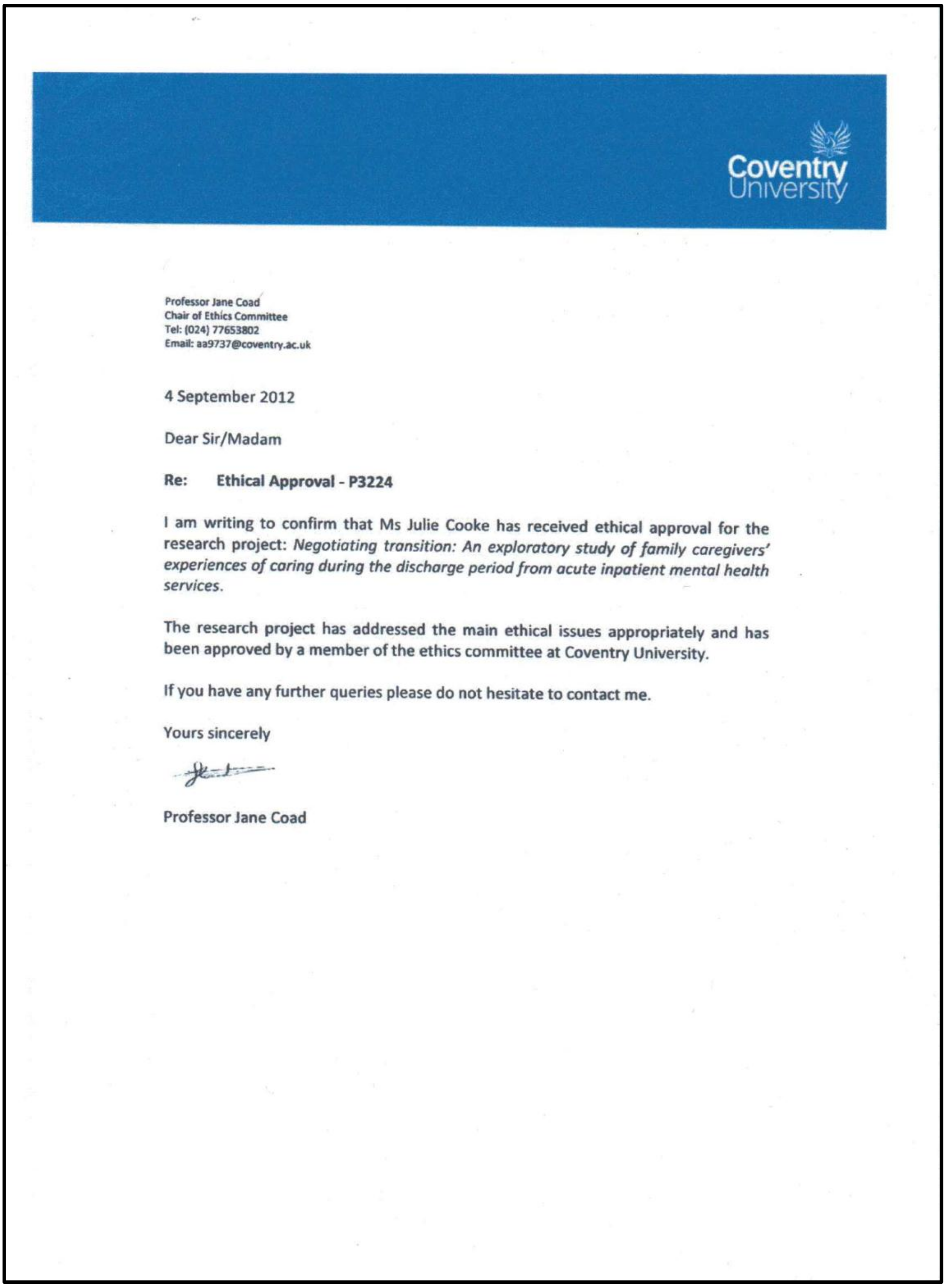
Tables and Figures. Tables and figures (illustrations) should not be embedded in the text, but should be included as separate files. A short descriptive title should appear above each table with a clear legend and any footnotes suitably identified below. All units must be included. Figures should be completely labeled, taking into account necessary size reduction. Captions should be typed, double spaced, in a separate file.

Proofs. Page proofs are sent electronically to the designated author. They must be carefully checked and returned within 48 hours of receipt.

Offprints. Free access to a pdf which can be sent or printed up to 50 times.

Appendix H

Confirmation of Coventry University ethical approval



Coventry University

Professor Jane Coad
Chair of Ethics Committee
Tel: (024) 77653802
Email: aa9737@coventry.ac.uk

4 September 2012

Dear Sir/Madam

Re: Ethical Approval - P3224

I am writing to confirm that Ms Julie Cooke has received ethical approval for the research project: *Negotiating transition: An exploratory study of family caregivers' experiences of caring during the discharge period from acute inpatient mental health services.*

The research project has addressed the main ethical issues appropriately and has been approved by a member of the ethics committee at Coventry University.

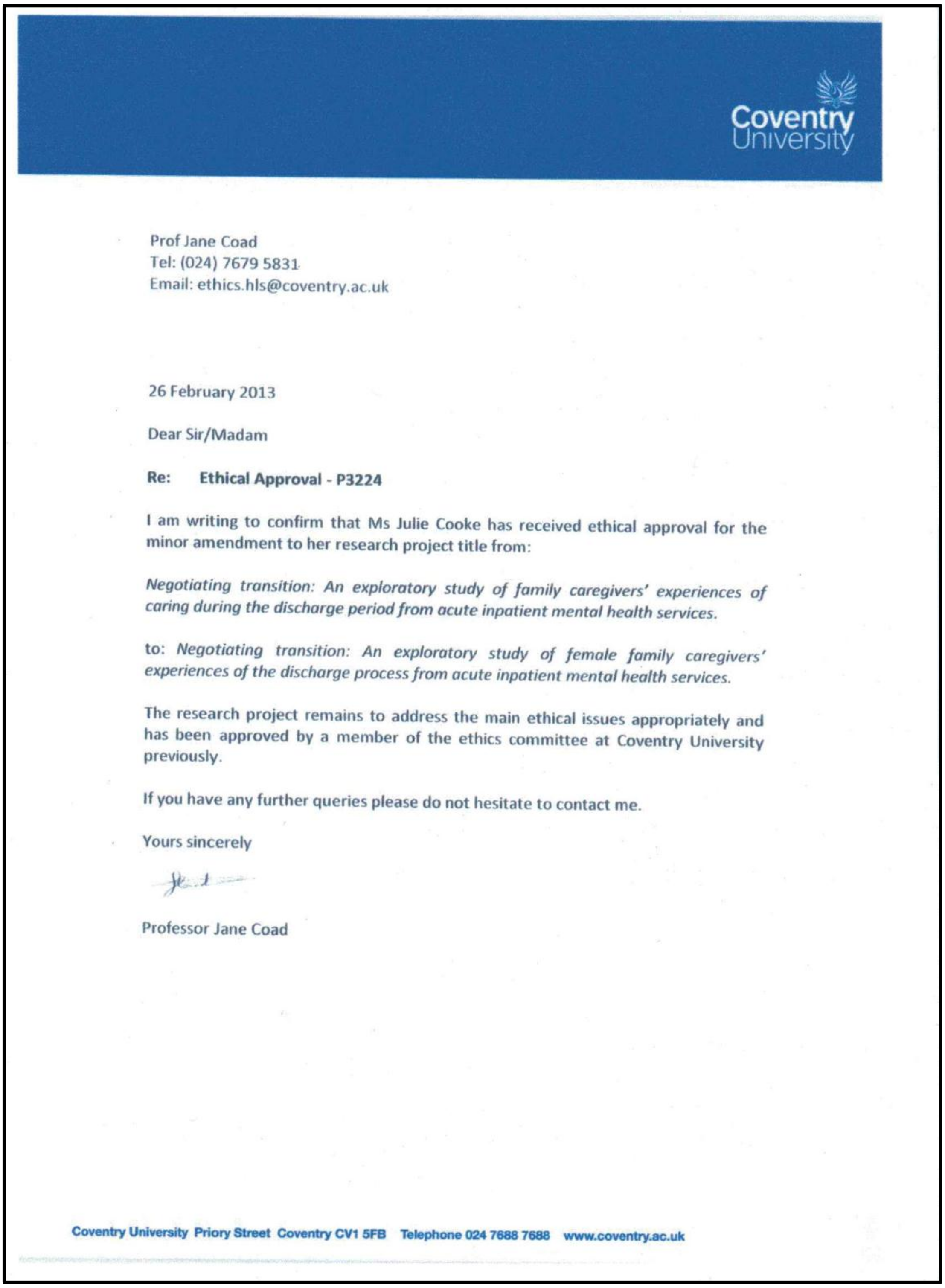
If you have any further queries please do not hesitate to contact me.

Yours sincerely

Professor Jane Coad

Appendix I

Updated confirmation of ethical approval from Coventry University



Coventry
University

Prof Jane Coad
Tel: (024) 7679 5831
Email: ethics.hls@coventry.ac.uk

26 February 2013

Dear Sir/Madam

Re: **Ethical Approval - P3224**

I am writing to confirm that Ms Julie Cooke has received ethical approval for the minor amendment to her research project title from:

Negotiating transition: An exploratory study of family caregivers' experiences of caring during the discharge period from acute inpatient mental health services.

to: *Negotiating transition: An exploratory study of female family caregivers' experiences of the discharge process from acute inpatient mental health services.*

The research project remains to address the main ethical issues appropriately and has been approved by a member of the ethics committee at Coventry University previously.

If you have any further queries please do not hesitate to contact me.

Yours sincerely

Professor Jane Coad

Coventry University Priory Street Coventry CV1 5FB Telephone 024 7688 7688 www.coventry.ac.uk

Appendix J

Letter from Guideposts Carer Support Service confirming their involvement

Guideposts
Leading the Way

Warwickshire Carer Support Service
Tel. 0845 600 9980
Fax. 02476 385666
www.guidepoststrust.org.uk
carerssupport@guidepoststrust.org.uk

Thursday 6th September 2012

Clincial Psychology Department
James Starley Building
Coventry University
Priory Street
Coventry
CV1 5FB

Dear Julie,

Re: Guideposts Carers Support Service

Thank you for approaching Guideposts Carer Support Service, regarding your doctoral research project entitled 'Negotiating transition: An exploratory study of female family carers' experiences of the discharge process from acute inpatient mental health services'.

Guideposts Carers Support Service provides support to over 5000 carers throughout Warwickshire and approximately 500 of these carers are people who support someone with a mental health condition (from mild to severe and enduring). As a service, we believe strongly in carer feedback and we are happy to support professionals carrying out research that is carer focussed.

I would like to confirm that we are in a position to support you with your research project and are more than happy to inform carers within our service of the work you will be carrying out over the next few months. If carers are interested in participating, we would then be able to provide them with the relevant participation instructions and signpost them to yourself.

In addition, we have received paperwork from Coventry University, which confirms that you have been granted ethical approval and we are therefore confident that all the relevant ethical issues have been appropriately addressed.

In the meantime, if you would like to discuss in more detail the type of support Guideposts Carers Support Service can offer to your research project, please feel free to contact the main office on 02476-385888.

Yours sincerely,

Vicki Farley
Mental Health Specialist Support Worker
Guideposts Carer Support Service

Reply to:
Guideposts Trust
44-45 Church Street
Nuneaton
Warwickshire
CV11 4AD

Registered Office: Guideposts Trust, Two Rivers, Station Lane, Witney, Oxfordshire, OX28 4BH
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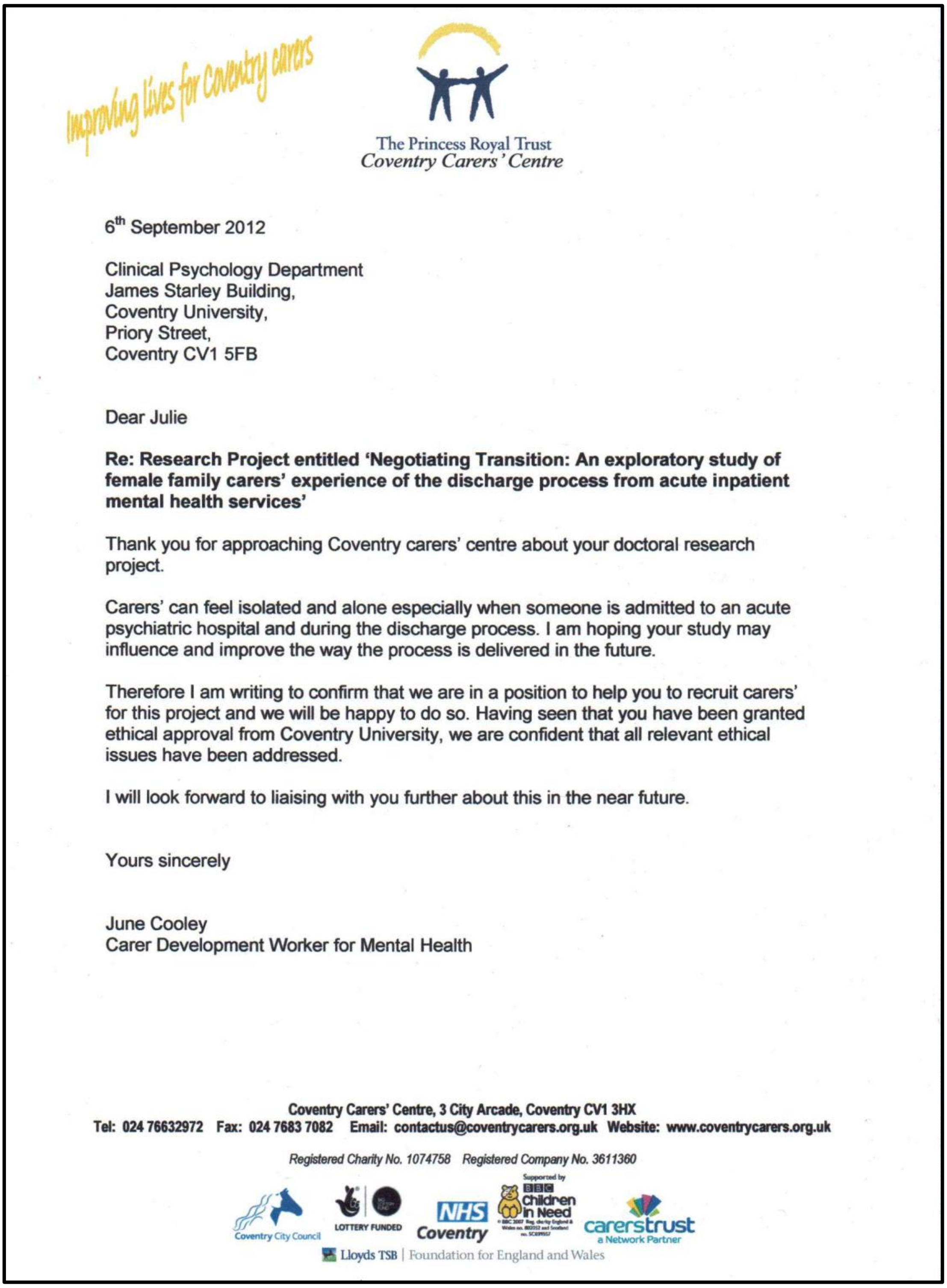
Appendix K

Letter from Coventry Carers' Centre confirming their involvement



Improving lives for Coventry carers

The Princess Royal Trust
Coventry Carers' Centre

6th September 2012

Clinical Psychology Department
James Starley Building,
Coventry University,
Priory Street,
Coventry CV1 5FB

Dear Julie

Re: Research Project entitled 'Negotiating Transition: An exploratory study of female family carers' experience of the discharge process from acute inpatient mental health services'

Thank you for approaching Coventry carers' centre about your doctoral research project.

Carers' can feel isolated and alone especially when someone is admitted to an acute psychiatric hospital and during the discharge process. I am hoping your study may influence and improve the way the process is delivered in the future.

Therefore I am writing to confirm that we are in a position to help you to recruit carers' for this project and we will be happy to do so. Having seen that you have been granted ethical approval from Coventry University, we are confident that all relevant ethical issues have been addressed.

I will look forward to liaising with you further about this in the near future.

Yours sincerely

June Cooley
Carer Development Worker for Mental Health

Coventry Carers' Centre, 3 City Arcade, Coventry CV1 3HX
Tel: 024 76632972 Fax: 024 7683 7082 Email: contactus@coventrycarers.org.uk Website: www.coventrycarers.org.uk

Registered Charity No. 1074758 Registered Company No. 3611360

Coventry City Council
LOTTERY FUNDED
NHS Coventry
Supported by BBC Children in Need
carerstrust a Network Partner
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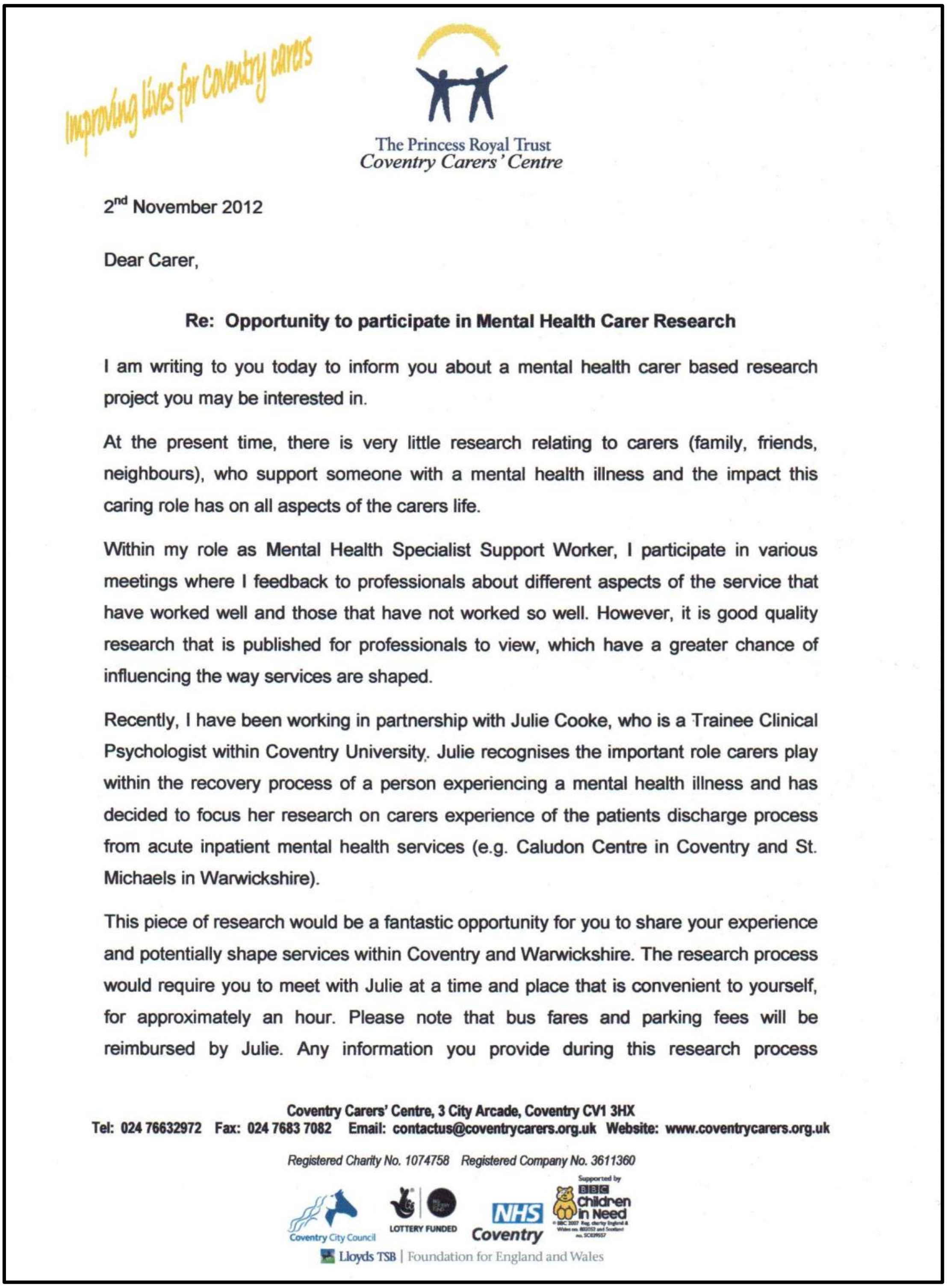
Appendix L

Letter to potential participants from Coventry Carers' Centre



Improving lives for Coventry carers

The Princess Royal Trust
Coventry Carers' Centre

2nd November 2012

Dear Carer,

Re: Opportunity to participate in Mental Health Carer Research

I am writing to you today to inform you about a mental health carer based research project you may be interested in.

At the present time, there is very little research relating to carers (family, friends, neighbours), who support someone with a mental health illness and the impact this caring role has on all aspects of the carers life.

Within my role as Mental Health Specialist Support Worker, I participate in various meetings where I feedback to professionals about different aspects of the service that have worked well and those that have not worked so well. However, it is good quality research that is published for professionals to view, which have a greater chance of influencing the way services are shaped.

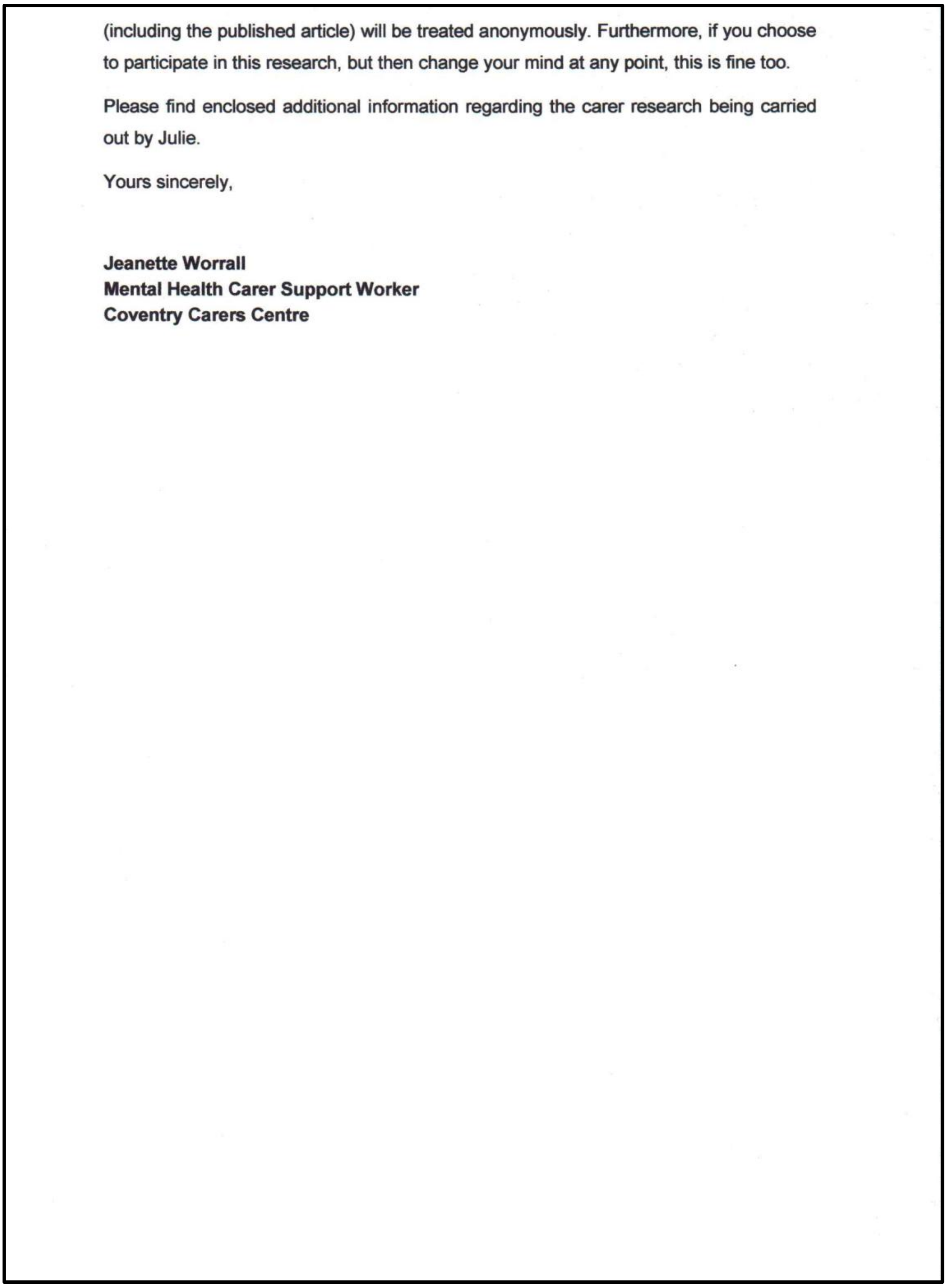
Recently, I have been working in partnership with Julie Cooke, who is a Trainee Clinical Psychologist within Coventry University. Julie recognises the important role carers play within the recovery process of a person experiencing a mental health illness and has decided to focus her research on carers experience of the patients discharge process from acute inpatient mental health services (e.g. Caludon Centre in Coventry and St. Michaels in Warwickshire).

This piece of research would be a fantastic opportunity for you to share your experience and potentially shape services within Coventry and Warwickshire. The research process would require you to meet with Julie at a time and place that is convenient to yourself, for approximately an hour. Please note that bus fares and parking fees will be reimbursed by Julie. Any information you provide during this research process

Coventry Carers' Centre, 3 City Arcade, Coventry CV1 3HX
Tel: 024 76632972 Fax: 024 7683 7082 Email: contactus@coventrycarers.org.uk Website: www.coventrycarers.org.uk

Registered Charity No. 1074758 Registered Company No. 3611360

Coventry City Council
LOTTERY FUNDED
NHS Coventry
Supported by BBC Children in Need
Lloyds TSB | Foundation for England and Wales



(including the published article) will be treated anonymously. Furthermore, if you choose to participate in this research, but then change your mind at any point, this is fine too.

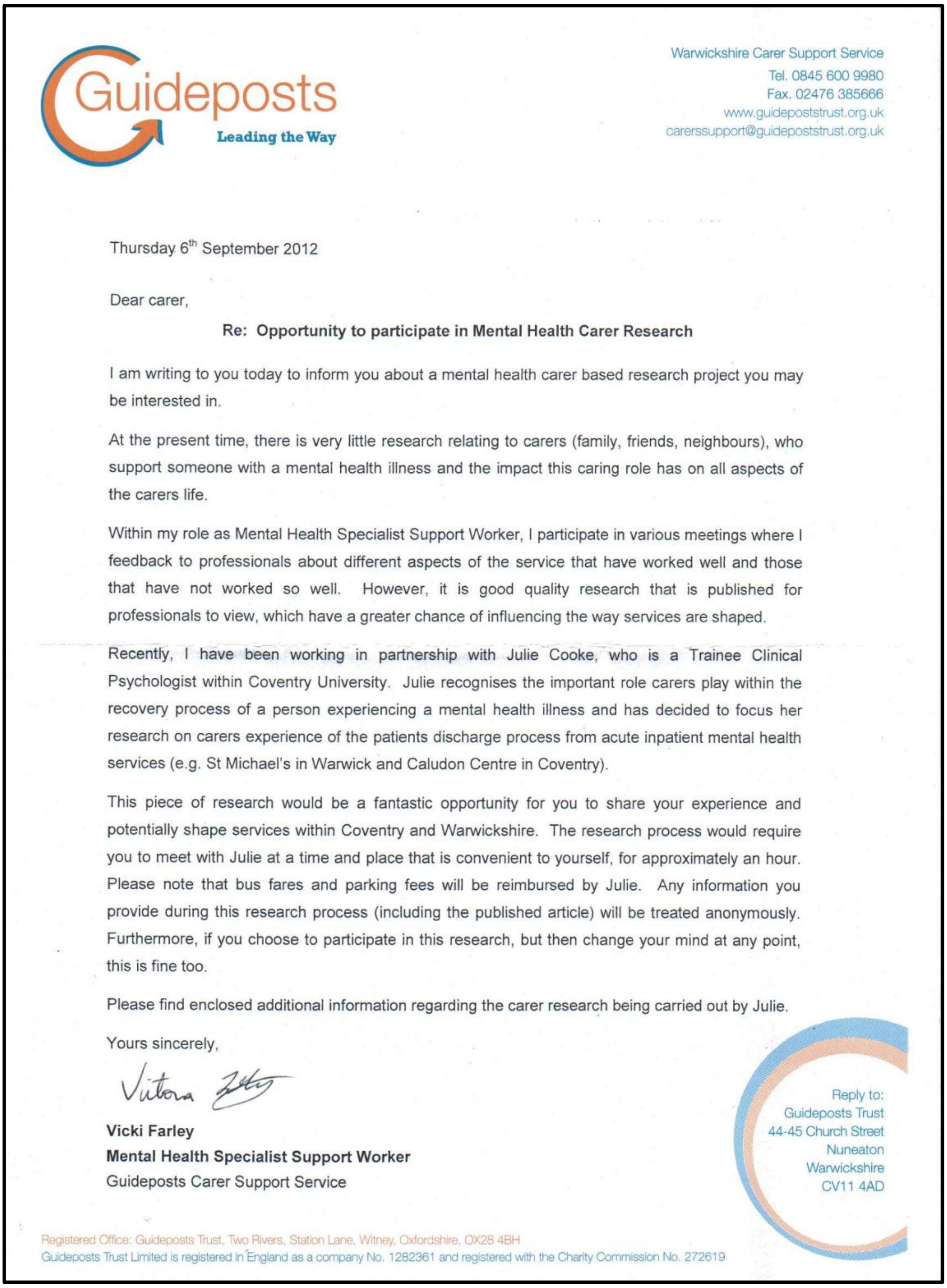
Please find enclosed additional information regarding the carer research being carried out by Julie.

Yours sincerely,

Jeanette Worrall
Mental Health Carer Support Worker
Coventry Carers Centre

Appendix M

Letter to potential participants from Guideposts Carer Support Service



Guideposts
Leading the Way

Warwickshire Carer Support Service
Tel. 0845 600 9980
Fax. 02476 385666
www.guideposstrust.org.uk
carerssupport@guidepoststrust.org.uk

Thursday 6th September 2012

Dear carer,

Re: Opportunity to participate in Mental Health Carer Research

I am writing to you today to inform you about a mental health carer based research project you may be interested in.

At the present time, there is very little research relating to carers (family, friends, neighbours), who support someone with a mental health illness and the impact this caring role has on all aspects of the carers life.

Within my role as Mental Health Specialist Support Worker, I participate in various meetings where I feedback to professionals about different aspects of the service that have worked well and those that have not worked so well. However, it is good quality research that is published for professionals to view, which have a greater chance of influencing the way services are shaped.

Recently, I have been working in partnership with Julie Cooke, who is a Trainee Clinical Psychologist within Coventry University. Julie recognises the important role carers play within the recovery process of a person experiencing a mental health illness and has decided to focus her research on carers experience of the patients discharge process from acute inpatient mental health services (e.g. St Michael's in Warwick and Caludon Centre in Coventry).

This piece of research would be a fantastic opportunity for you to share your experience and potentially shape services within Coventry and Warwickshire. The research process would require you to meet with Julie at a time and place that is convenient to yourself, for approximately an hour. Please note that bus fares and parking fees will be reimbursed by Julie. Any information you provide during this research process (including the published article) will be treated anonymously. Furthermore, if you choose to participate in this research, but then change your mind at any point, this is fine too.

Please find enclosed additional information regarding the carer research being carried out by Julie.

Yours sincerely,

Victoria

Vicki Farley
Mental Health Specialist Support Worker
Guideposts Carer Support Service

Reply to:
Guideposts Trust
44-45 Church Street
Nuneaton
Warwickshire
CV11 4AD

Registered Office: Guideposts Trust, Two Rivers, Station Lane, Witney, Oxfordshire, OX28 4BH
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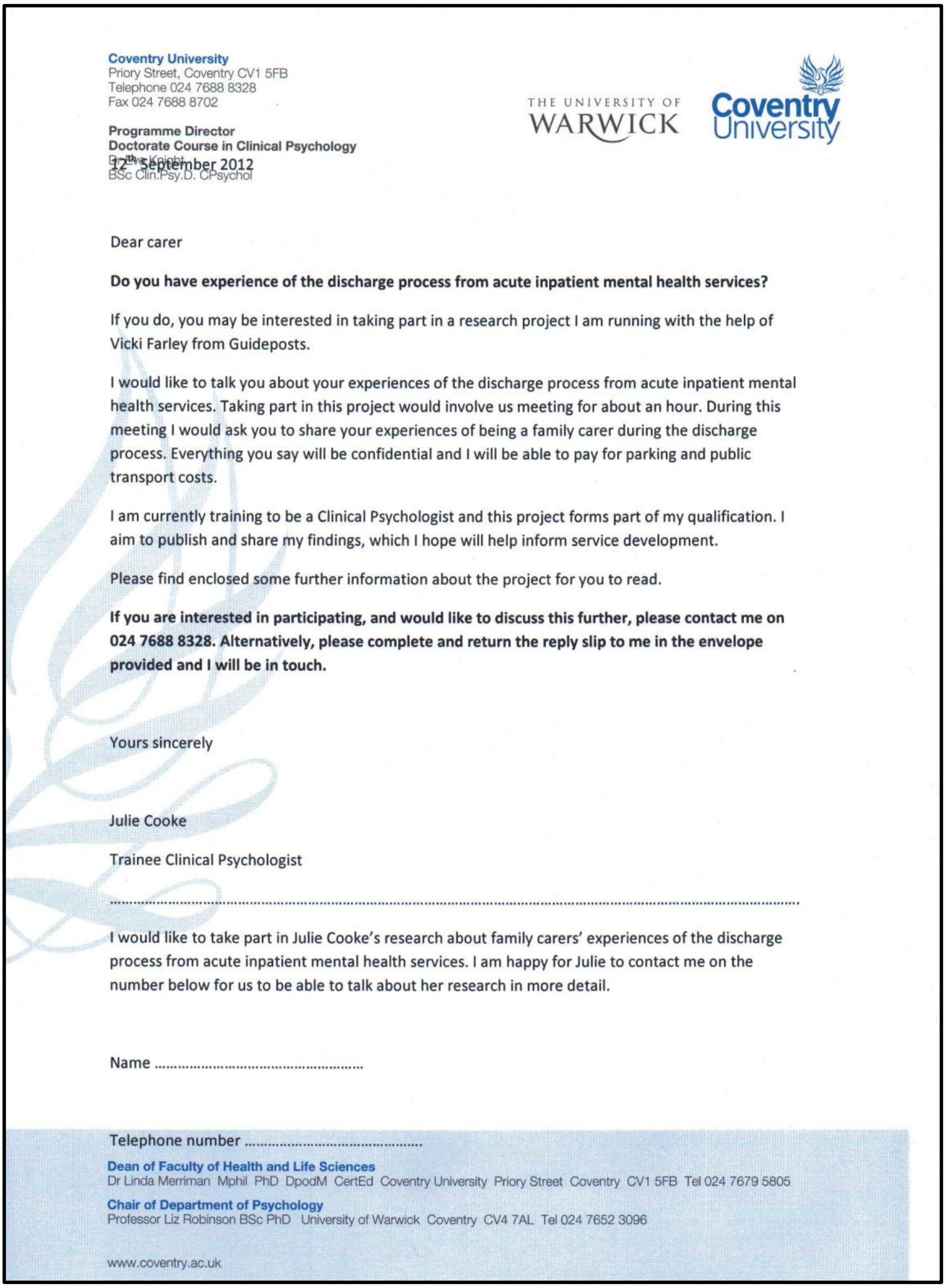
Appendix N

Letter to potential participants from the principal researcher



Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF WARWICK
Coventry University

12th September 2012

Dear carer

Do you have experience of the discharge process from acute inpatient mental health services?

If you do, you may be interested in taking part in a research project I am running with the help of Vicki Farley from Guideposts.

I would like to talk you about your experiences of the discharge process from acute inpatient mental health services. Taking part in this project would involve us meeting for about an hour. During this meeting I would ask you to share your experiences of being a family carer during the discharge process. Everything you say will be confidential and I will be able to pay for parking and public transport costs.

I am currently training to be a Clinical Psychologist and this project forms part of my qualification. I aim to publish and share my findings, which I hope will help inform service development.

Please find enclosed some further information about the project for you to read.

If you are interested in participating, and would like to discuss this further, please contact me on 024 7688 8328. Alternatively, please complete and return the reply slip to me in the envelope provided and I will be in touch.

Yours sincerely

Julie Cooke

Trainee Clinical Psychologist

……

I would like to take part in Julie Cooke's research about family carers' experiences of the discharge process from acute inpatient mental health services. I am happy for Julie to contact me on the number below for us to be able to talk about her research in more detail.

Name ……………………………………………

Telephone number ……………………………………

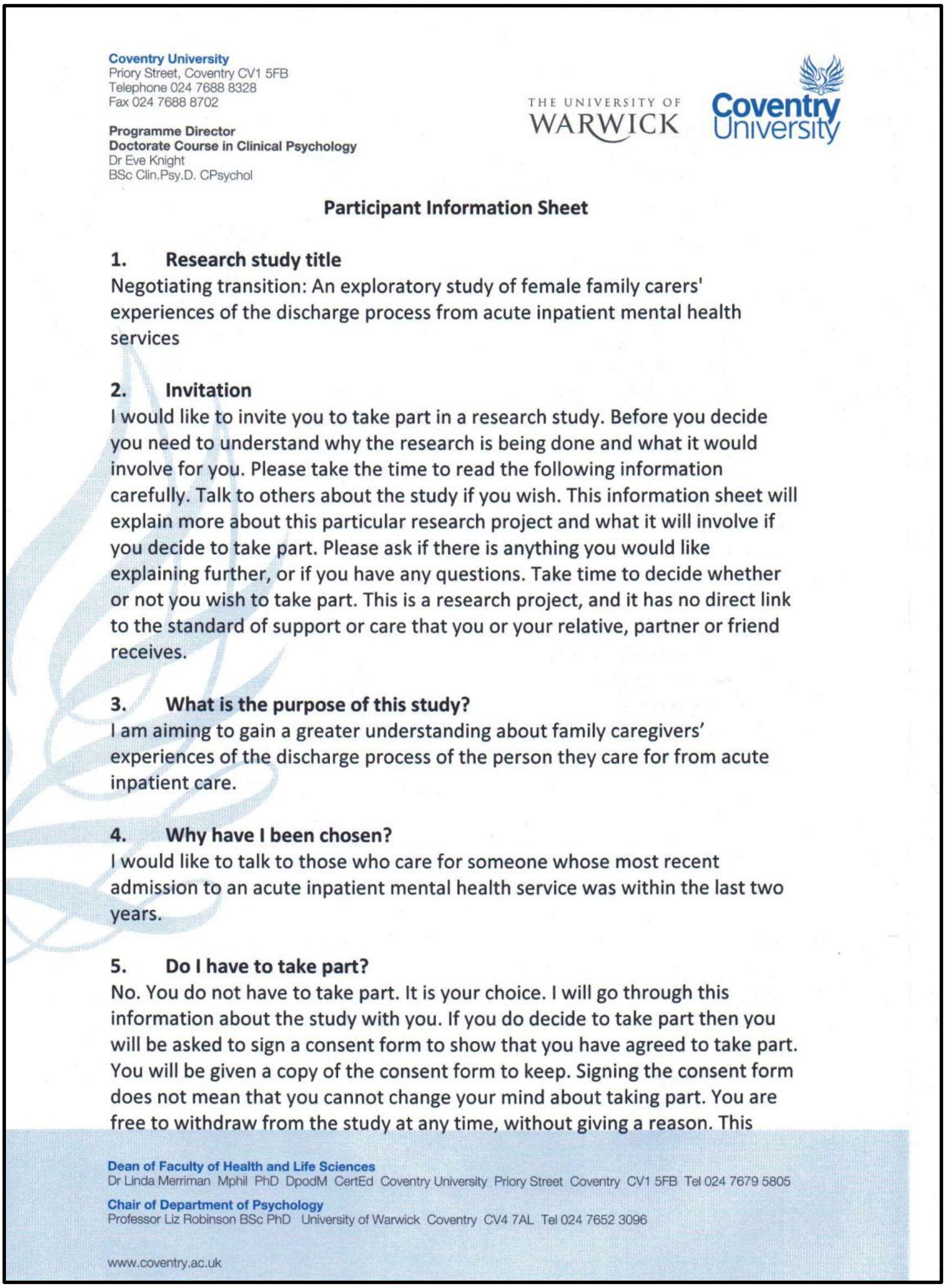
Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Chair of Department of Psychology
Professor Liz Robinson BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

www.coventry.ac.uk

Appendix O

Participant information sheet



Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

Participant Information Sheet

1. Research study title

Negotiating transition: An exploratory study of female family carers' experiences of the discharge process from acute inpatient mental health services

2. Invitation

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish. This information sheet will explain more about this particular research project and what it will involve if you decide to take part. Please ask if there is anything you would like explaining further, or if you have any questions. Take time to decide whether or not you wish to take part. This is a research project, and it has no direct link to the standard of support or care that you or your relative, partner or friend receives.

3. What is the purpose of this study?

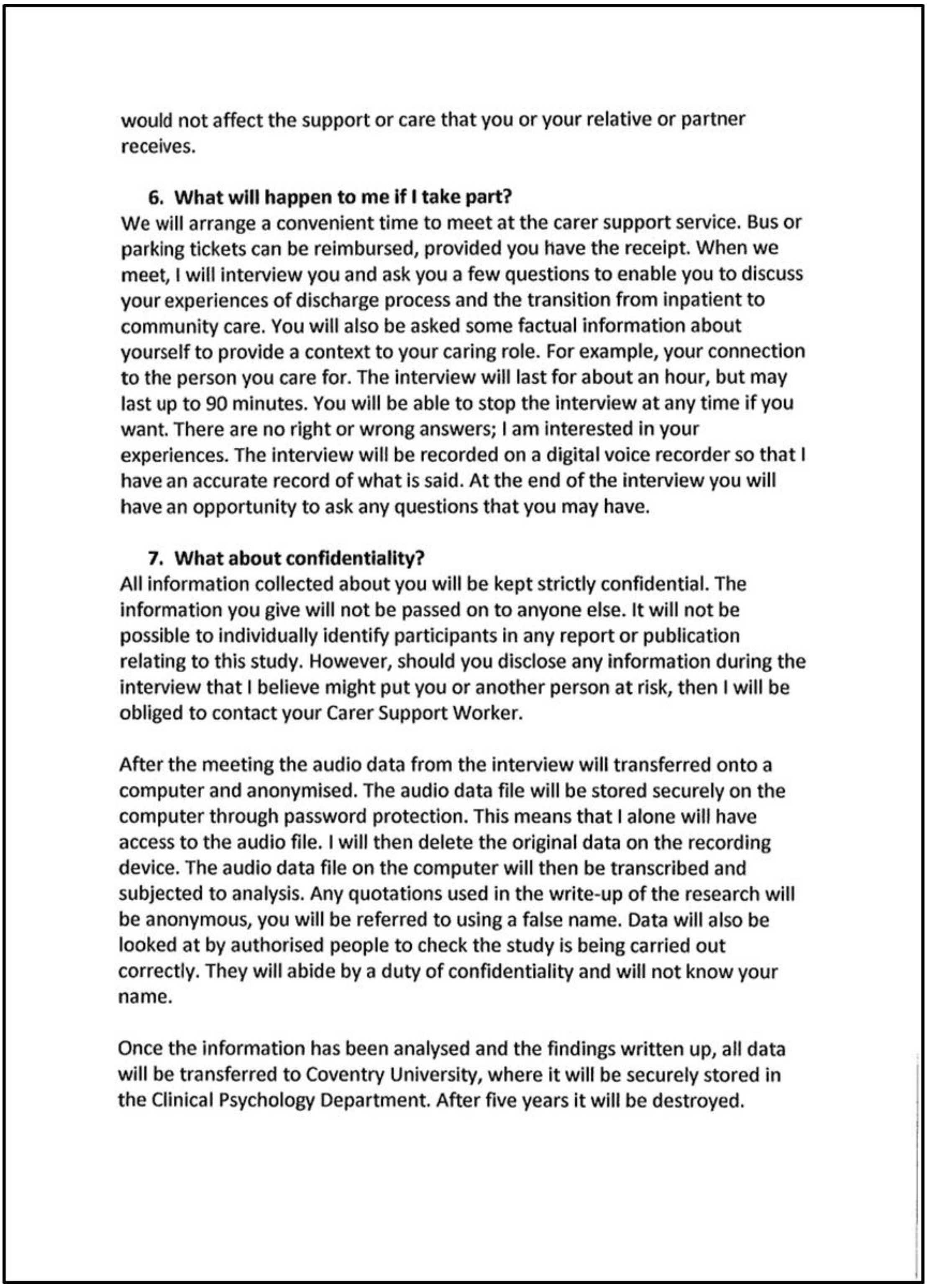
I am aiming to gain a greater understanding about family caregivers' experiences of the discharge process of the person they care for from acute inpatient care.

4. Why have I been chosen?

I would like to talk to those who care for someone whose most recent admission to an acute inpatient mental health service was within the last two years.

5. Do I have to take part?

No. You do not have to take part. It is your choice. I will go through this information about the study with you. If you do decide to take part then you will be asked to sign a consent form to show that you have agreed to take part. You will be given a copy of the consent form to keep. Signing the consent form does not mean that you cannot change your mind about taking part. You are free to withdraw from the study at any time, without giving a reason. This



would not affect the support or care that you or your relative or partner receives.

6. What will happen to me if I take part?

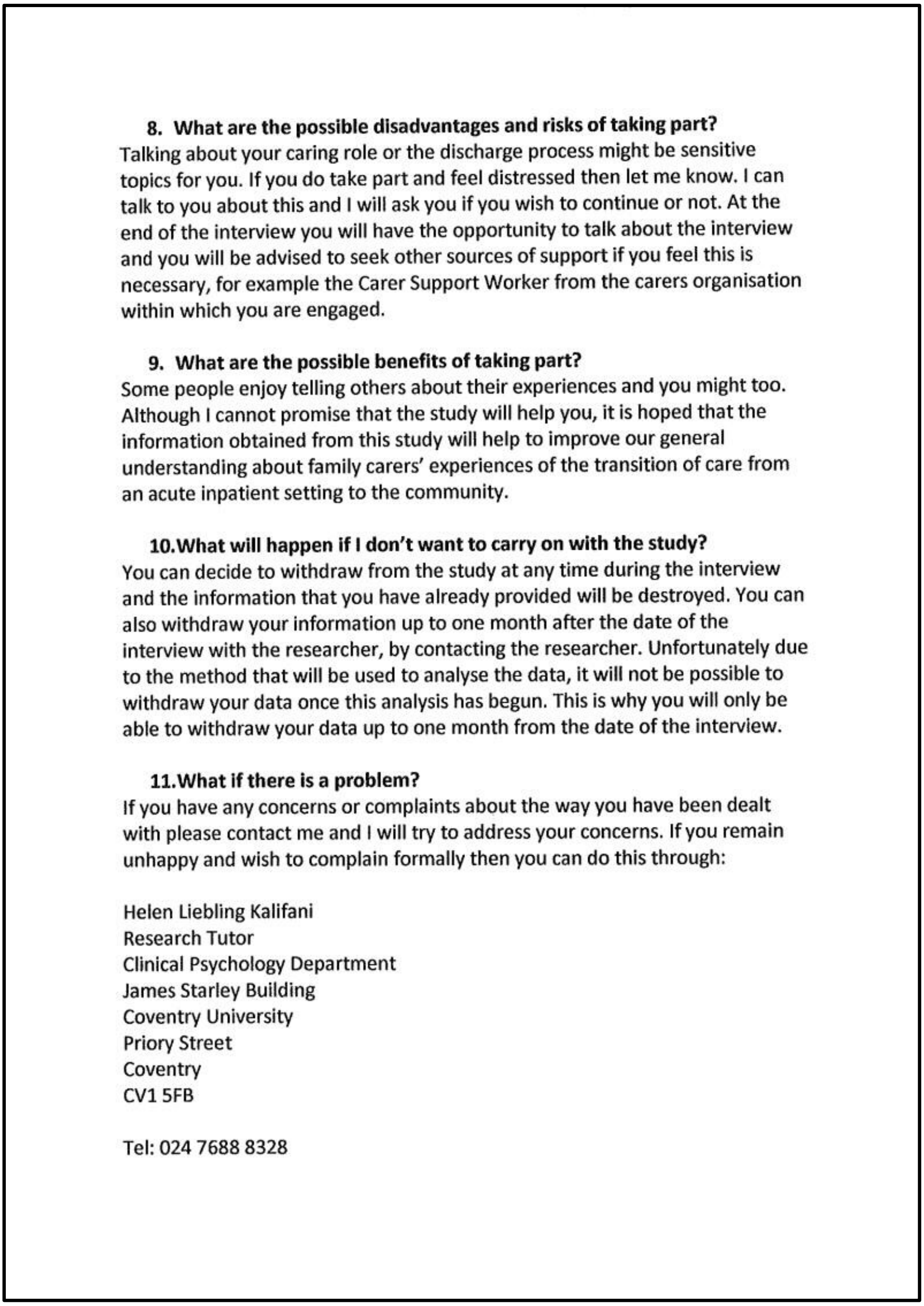
We will arrange a convenient time to meet at the carer support service. Bus or parking tickets can be reimbursed, provided you have the receipt. When we meet, I will interview you and ask you a few questions to enable you to discuss your experiences of discharge process and the transition from inpatient to community care. You will also be asked some factual information about yourself to provide a context to your caring role. For example, your connection to the person you care for. The interview will last for about an hour, but may last up to 90 minutes. You will be able to stop the interview at any time if you want. There are no right or wrong answers; I am interested in your experiences. The interview will be recorded on a digital voice recorder so that I have an accurate record of what is said. At the end of the interview you will have an opportunity to ask any questions that you may have.

7. What about confidentiality?

All information collected about you will be kept strictly confidential. The information you give will not be passed on to anyone else. It will not be possible to individually identify participants in any report or publication relating to this study. However, should you disclose any information during the interview that I believe might put you or another person at risk, then I will be obliged to contact your Carer Support Worker.

After the meeting the audio data from the interview will transferred onto a computer and anonymised. The audio data file will be stored securely on the computer through password protection. This means that I alone will have access to the audio file. I will then delete the original data on the recording device. The audio data file on the computer will then be transcribed and subjected to analysis. Any quotations used in the write-up of the research will be anonymous, you will be referred to using a false name. Data will also be looked at by authorised people to check the study is being carried out correctly. They will abide by a duty of confidentiality and will not know your name.

Once the information has been analysed and the findings written up, all data will be transferred to Coventry University, where it will be securely stored in the Clinical Psychology Department. After five years it will be destroyed.



8. What are the possible disadvantages and risks of taking part?

Talking about your caring role or the discharge process might be sensitive topics for you. If you do take part and feel distressed then let me know. I can talk to you about this and I will ask you if you wish to continue or not. At the end of the interview you will have the opportunity to talk about the interview and you will be advised to seek other sources of support if you feel this is necessary, for example the Carer Support Worker from the carers organisation within which you are engaged.

9. What are the possible benefits of taking part?

Some people enjoy telling others about their experiences and you might too. Although I cannot promise that the study will help you, it is hoped that the information obtained from this study will help to improve our general understanding about family carers' experiences of the transition of care from an acute inpatient setting to the community.

10. What will happen if I don't want to carry on with the study?

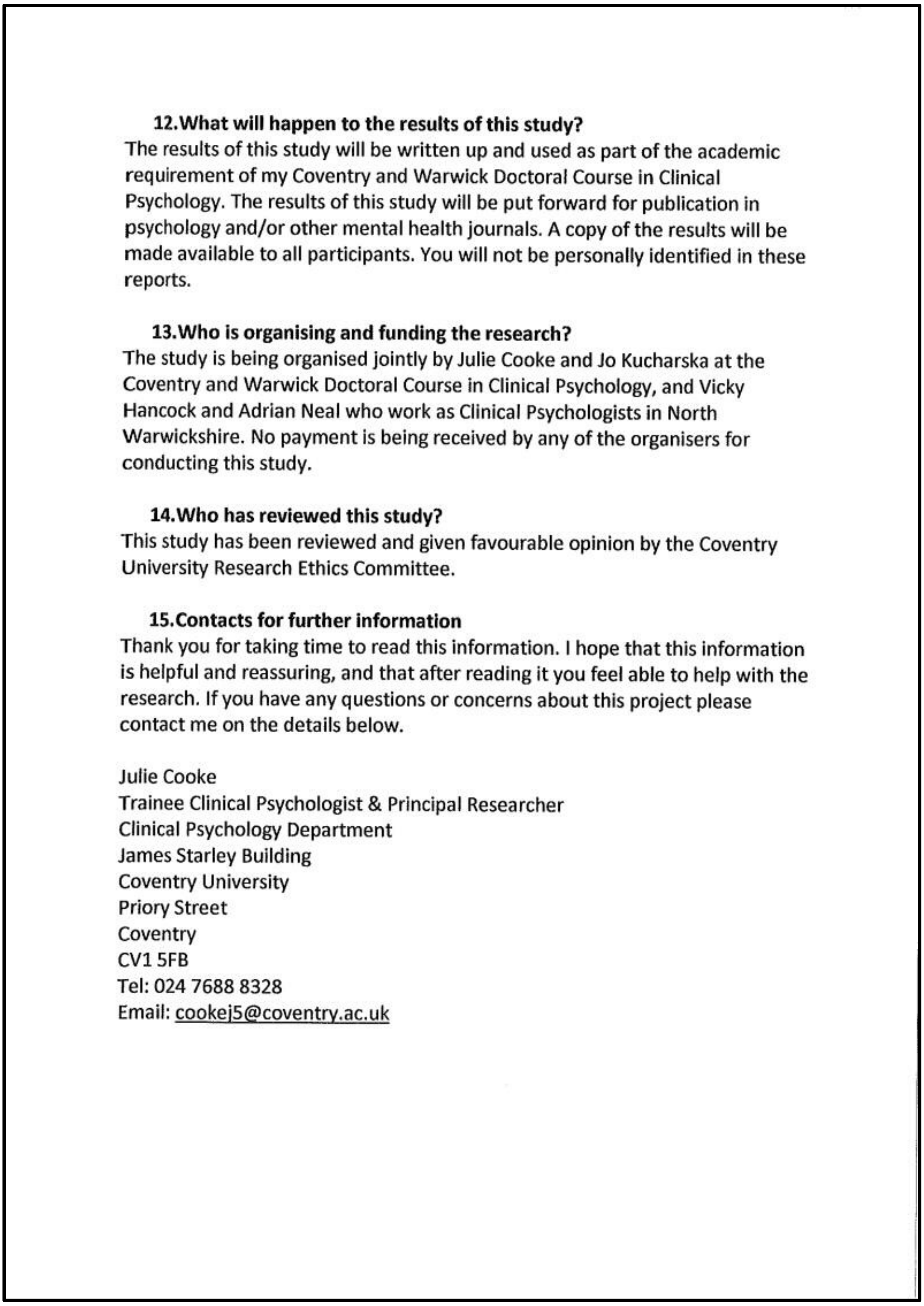
You can decide to withdraw from the study at any time during the interview and the information that you have already provided will be destroyed. You can also withdraw your information up to one month after the date of the interview with the researcher, by contacting the researcher. Unfortunately due to the method that will be used to analyse the data, it will not be possible to withdraw your data once this analysis has begun. This is why you will only be able to withdraw your data up to one month from the date of the interview.

11. What if there is a problem?

If you have any concerns or complaints about the way you have been dealt with please contact me and I will try to address your concerns. If you remain unhappy and wish to complain formally then you can do this through:

Helen Liebling Kalifani
Research Tutor
Clinical Psychology Department
James Starley Building
Coventry University
Priory Street
Coventry
CV1 5FB

Tel: 024 7688 8328



12. What will happen to the results of this study?

The results of this study will be written up and used as part of the academic requirement of my Coventry and Warwick Doctoral Course in Clinical Psychology. The results of this study will be put forward for publication in psychology and/or other mental health journals. A copy of the results will be made available to all participants. You will not be personally identified in these reports.

13. Who is organising and funding the research?

The study is being organised jointly by Julie Cooke and Jo Kucharska at the Coventry and Warwick Doctoral Course in Clinical Psychology, and Vicky Hancock and Adrian Neal who work as Clinical Psychologists in North Warwickshire. No payment is being received by any of the organisers for conducting this study.

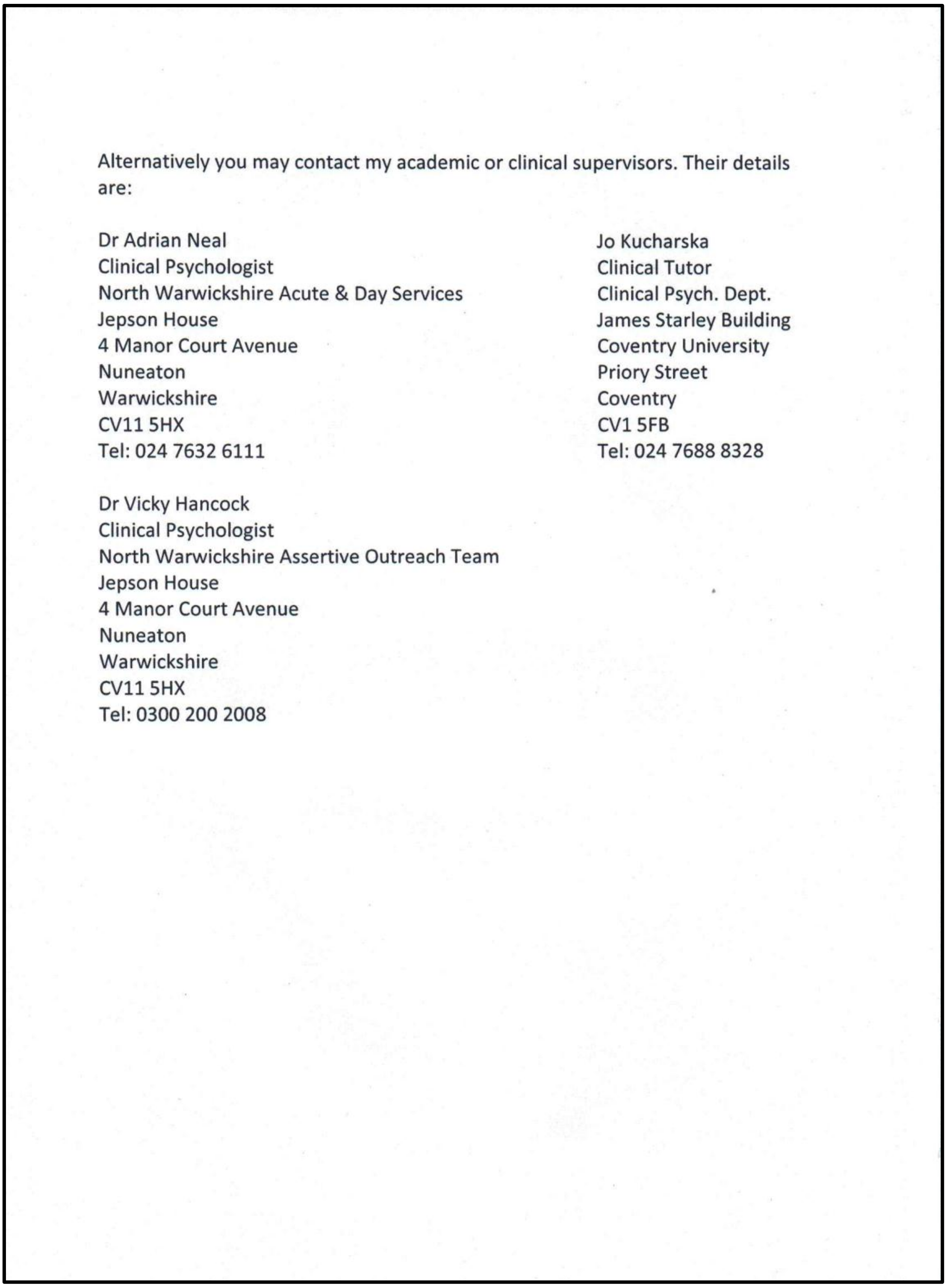
14. Who has reviewed this study?

This study has been reviewed and given favourable opinion by the Coventry University Research Ethics Committee.

15. Contacts for further information

Thank you for taking time to read this information. I hope that this information is helpful and reassuring, and that after reading it you feel able to help with the research. If you have any questions or concerns about this project please contact me on the details below.

Julie Cooke
Trainee Clinical Psychologist & Principal Researcher
Clinical Psychology Department
James Starley Building
Coventry University
Priory Street
Coventry
CV1 5FB
Tel: 024 7688 8328
Email: cookej5@coventry.ac.uk



Alternatively you may contact my academic or clinical supervisors. Their details are:

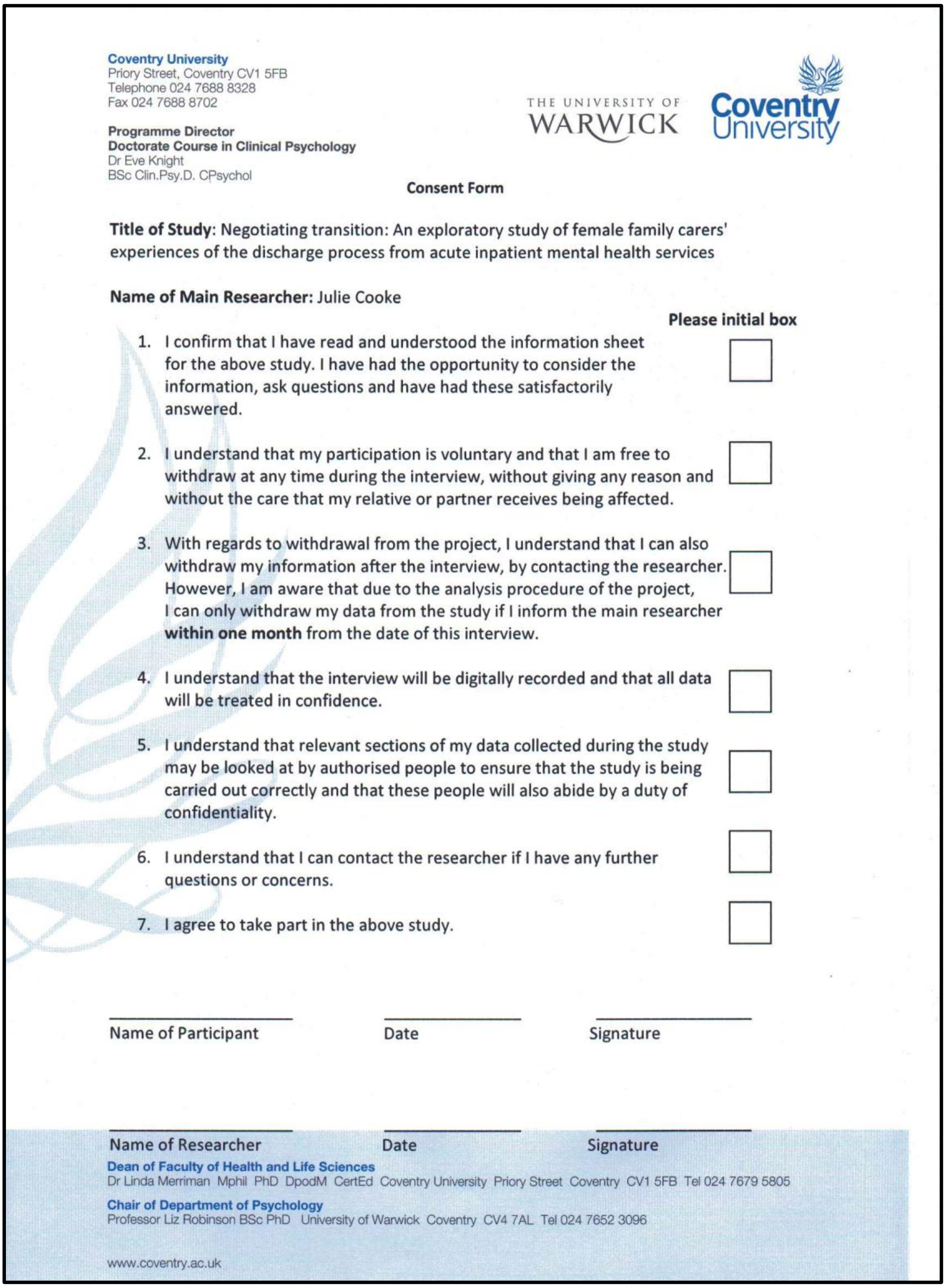
Dr Adrian Neal
Clinical Psychologist
North Warwickshire Acute & Day Services
Jepson House
4 Manor Court Avenue
Nuneaton
Warwickshire
CV11 5HX
Tel: 024 7632 6111

Jo Kucharska
Clinical Tutor
Clinical Psych. Dept.
James Starley Building
Coventry University
Priory Street
Coventry
CV1 5FB
Tel: 024 7688 8328

Dr Vicky Hancock
Clinical Psychologist
North Warwickshire Assertive Outreach Team
Jepson House
4 Manor Court Avenue
Nuneaton
Warwickshire
CV11 5HX
Tel: 0300 200 2008

Appendix P

Consent form



Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF WARWICK

Coventry University

Consent Form

Title of Study: Negotiating transition: An exploratory study of female family carers' experiences of the discharge process from acute inpatient mental health services

Name of Main Researcher: Julie Cooke

Please initial box

1. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these satisfactorily answered. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time during the interview, without giving any reason and without the care that my relative or partner receives being affected. ☐
3. With regards to withdrawal from the project, I understand that I can also withdraw my information after the interview, by contacting the researcher. However, I am aware that due to the analysis procedure of the project, I can only withdraw my data from the study if I inform the main researcher **within one month** from the date of this interview. ☐
4. I understand that the interview will be digitally recorded and that all data will be treated in confidence. ☐
5. I understand that relevant sections of my data collected during the study may be looked at by authorised people to ensure that the study is being carried out correctly and that these people will also abide by a duty of confidentiality. ☐
6. I understand that I can contact the researcher if I have any further questions or concerns. ☐
7. I agree to take part in the above study. ☐

____________________	______________	________________
Name of Participant	Date	Signature
____________________	______________	________________
Name of Researcher	Date	Signature

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Chair of Department of Psychology
Professor Liz Robinson BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

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Appendix Q

Semi-structured interview schedule

Introduction Questions

Can you tell me about yourself and your caring role?

Prompts:

- How long have you been a carer?
- How has your caring role changed over time?

Can you tell me about the person you care for?

Prompts:

- What is your relationship to the person you care for?
- What kinds of mental health difficulties has you family member experienced/been experiencing?

Section 1

Can you tell me about the last time your family member was hospitalised?

Prompts:

- How long ago was this?
- What was it like for you?
- What was your involvement when your family member was in hospital?

Section 2

Can you tell me about the preparation for your family member's discharge?

Prompts:

- How was the discharge planning process arranged?
- What was your involvement in the discharge planning process?
- Did you feel your views and opinions were listened to during the discharge process?
- What was this stage in the process like for you?

Section 3

Can you tell me what it was like for you when your family member was discharged?

Prompts:

- How long was you family member hospitalised for?
- Had you been given time to prepare for the discharge day?
- How did you feel about your family members discharge?
- Were any follow-up care procedures in place?

Section 4

How do you think your family member was prepared for the discharge?

Prompts:

- How did they feel about the treatment they had received?
- Did they feel different compared to when they had been admitted to hospital?
- Were they in agreement with the decision to discharge?

Section 5

Can you tell me what it was like for you during the first few months after discharge?

Prompts:

- What were your concerns/worries/fears/hopes during this time?
- How was your relationship with your family member during this time?
- Do you think anything changed as a result of your family member being hospitalised?
- What was the impact of discharge on your work, finances, social life, and everyday life?

Section 6

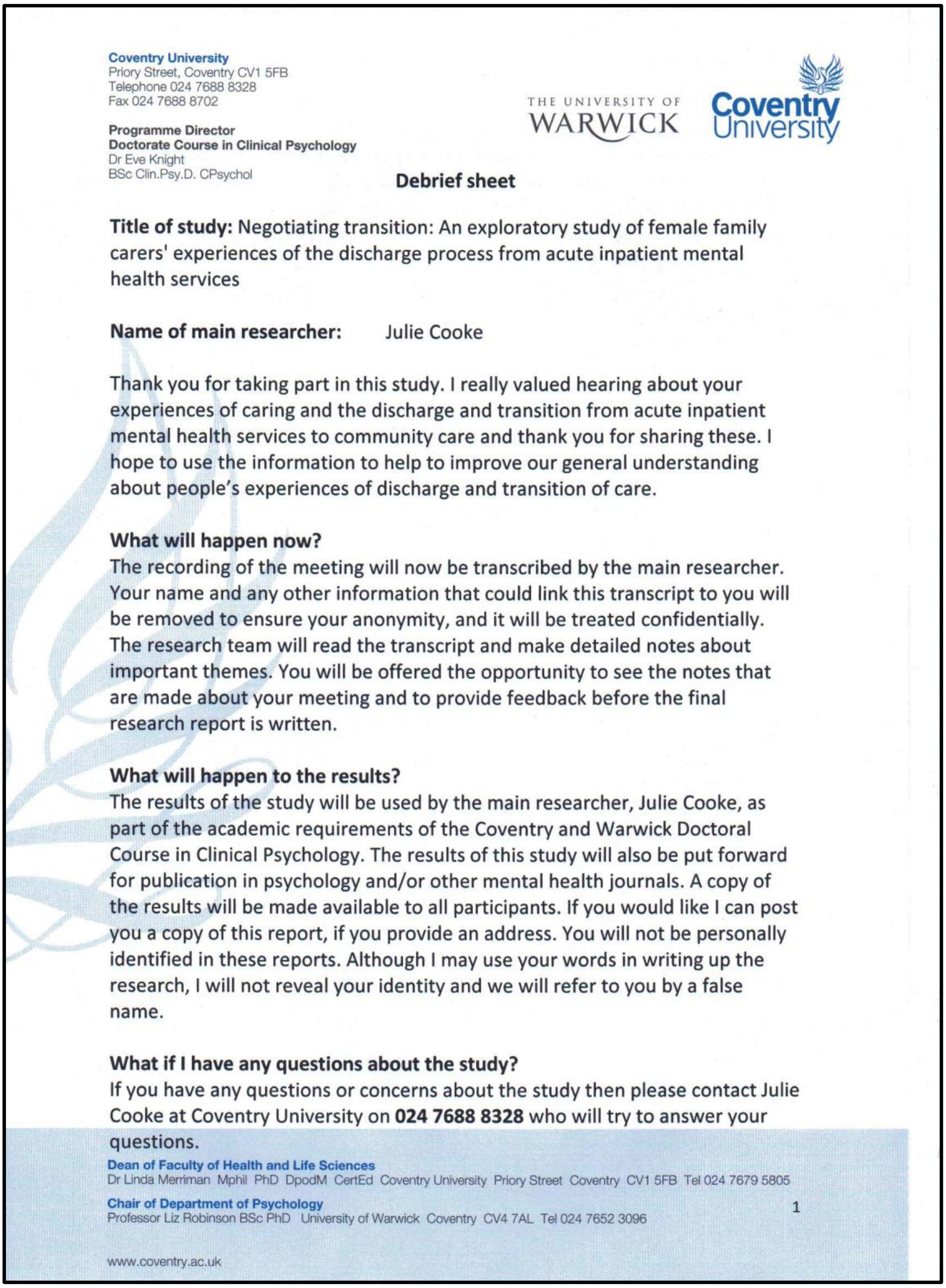
Looking back over the discharge and transition as a whole, what did you find helpful or unhelpful during this time?

Prompts:

- What about the support from hospital, community, carer support service?
- What would have helped you feel more able to fulfil your caring duties?
- Were there any other factors that made the transition from hospital to community easier/more difficult?
- Do you have any suggestions for what may have made the process of discharge from hospital to the community easier or smoother?

Appendix R

Debrief sheet



Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF WARWICK

Coventry University

Debrief sheet

Title of study: Negotiating transition: An exploratory study of female family carers' experiences of the discharge process from acute inpatient mental health services

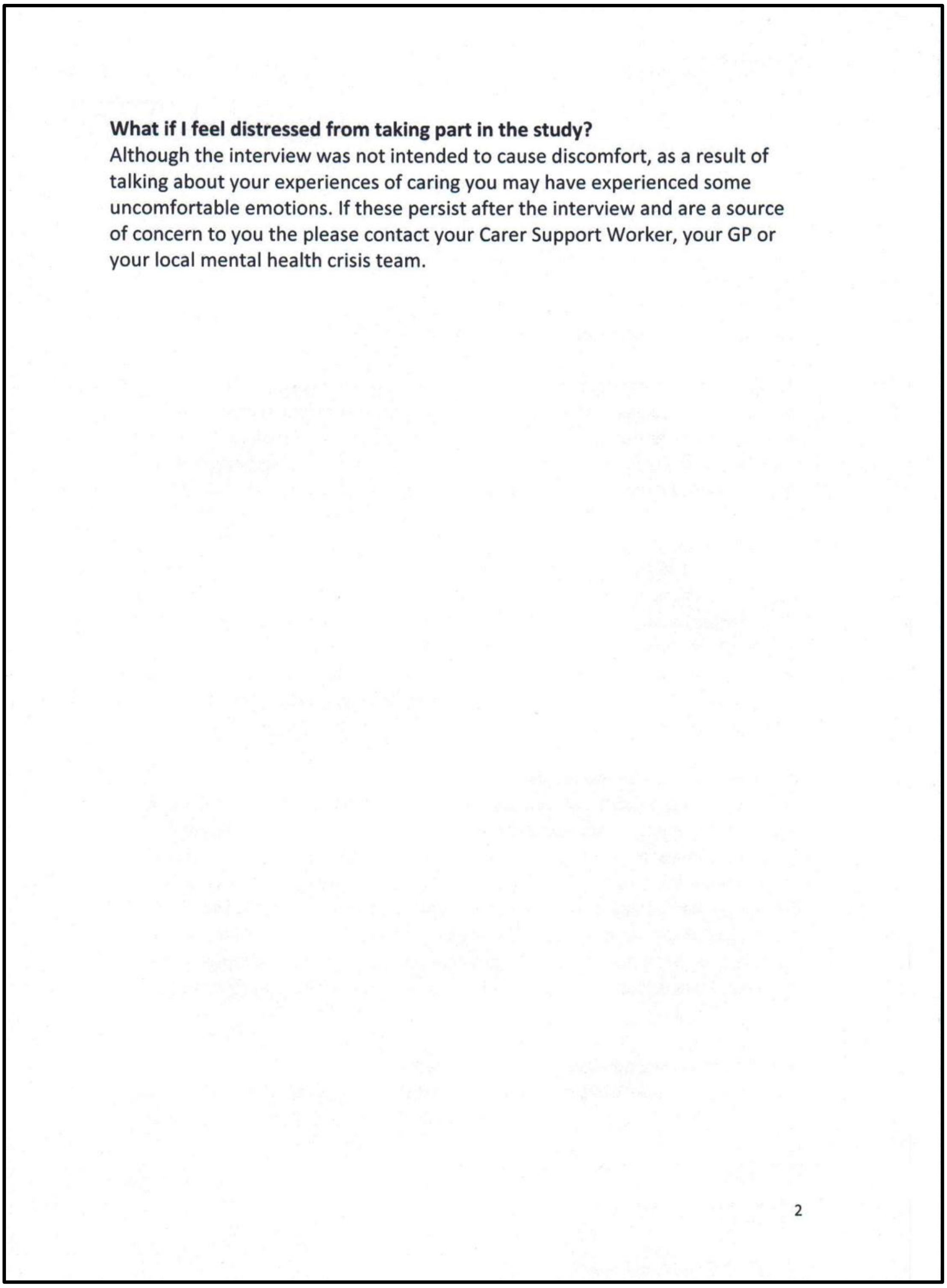
Name of main researcher: Julie Cooke

Thank you for taking part in this study. I really valued hearing about your experiences of caring and the discharge and transition from acute inpatient mental health services to community care and thank you for sharing these. I hope to use the information to help to improve our general understanding about people's experiences of discharge and transition of care.

What will happen now?
The recording of the meeting will now be transcribed by the main researcher. Your name and any other information that could link this transcript to you will be removed to ensure your anonymity, and it will be treated confidentially. The research team will read the transcript and make detailed notes about important themes. You will be offered the opportunity to see the notes that are made about your meeting and to provide feedback before the final research report is written.

What will happen to the results?
The results of the study will be used by the main researcher, Julie Cooke, as part of the academic requirements of the Coventry and Warwick Doctoral Course in Clinical Psychology. The results of this study will also be put forward for publication in psychology and/or other mental health journals. A copy of the results will be made available to all participants. If you would like I can post you a copy of this report, if you provide an address. You will not be personally identified in these reports. Although I may use your words in writing up the research, I will not reveal your identity and we will refer to you by a false name.

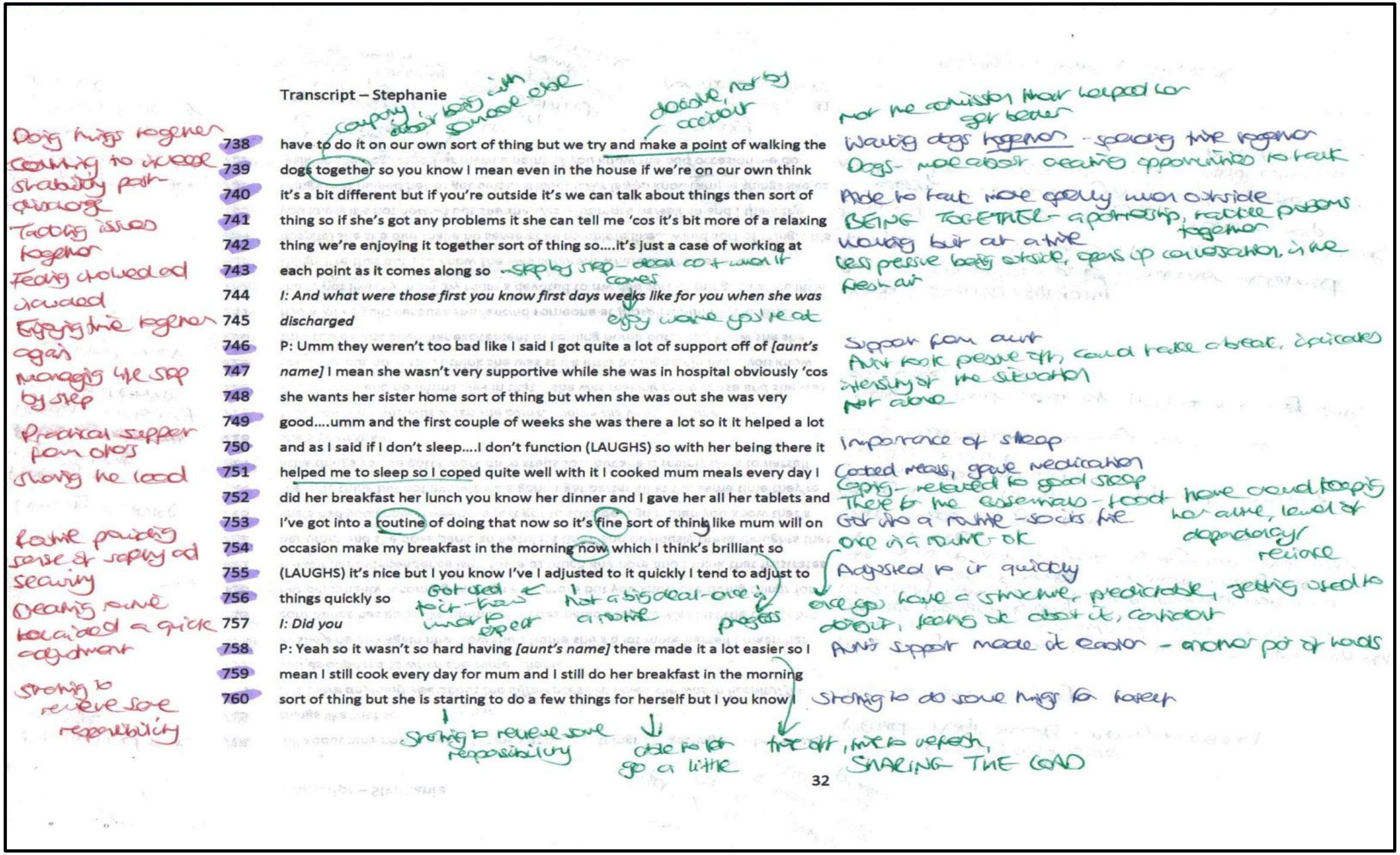
What if I have any questions about the study?
If you have any questions or concerns about the study then please contact Julie Cooke at Coventry University on **024 7688 8328** who will try to answer your questions.



What if I feel distressed from taking part in the study?
Although the interview was not intended to cause discomfort, as a result of talking about your experiences of caring you may have experienced some uncomfortable emotions. If these persist after the interview and are a source of concern to you the please contact your Carer Support Worker, your GP or your local mental health crisis team.

Appendix S

Example of coding a transcript using IPA



Transcript – Stephanie

have to do it on our own sort of thing but we try and make a point of walking the dogs together so you know I mean even in the house if we're on our own think it's a bit different but if you're outside it's we can talk about things then sort of thing so if she's got any problems it she can tell me 'cos it's bit more of a relaxing thing we're enjoying it together sort of thing so....it's just a case of working at each point as it comes along so

I: And what were those first you know first days weeks like for you when she was discharged

P: Umm they weren't too bad like I said I got quite a lot of support off of *[aunt's name]* I mean she wasn't very supportive while she was in hospital obviously 'cos she wants her sister home sort of thing but when she was out she was very good....umm and the first couple of weeks she was there a lot so it helped a lot and as I said if I don't sleep....I don't function (LAUGHS) so with her being there it helped me to sleep so I coped quite well with it I cooked mum meals every day I did her breakfast her lunch you know her dinner and I gave her all her tablets and I've got into a routine of doing that now so it's fine sort of think like mum will on occasion make my breakfast in the morning now which I think's brilliant so (LAUGHS) it's nice but I you know I've I adjusted to it quickly I tend to adjust to things quickly so

I: Did you

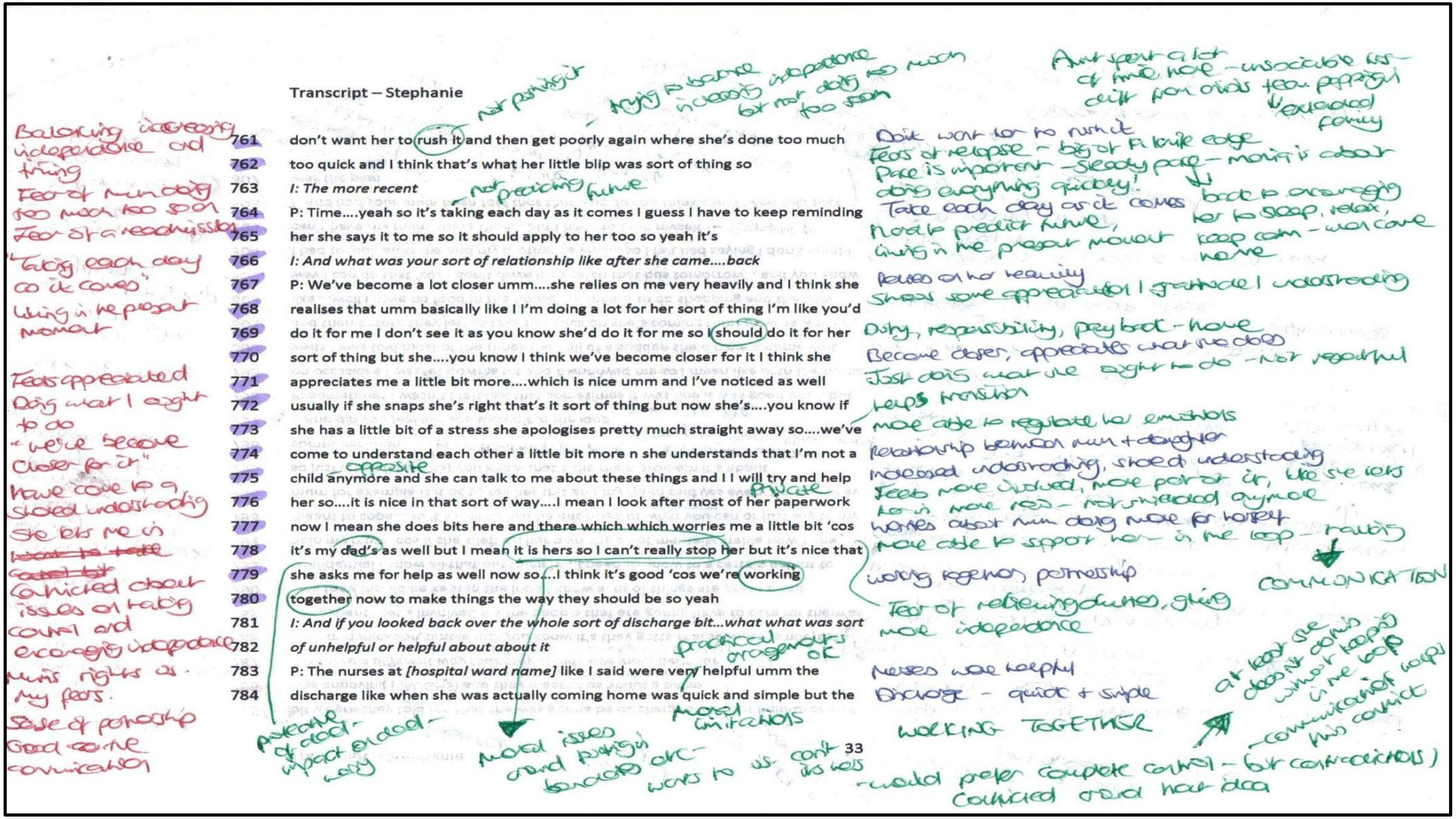
P: Yeah so it wasn't so hard having *[aunt's name]* there made it a lot easier so I mean I still cook every day for mum and I still do her breakfast in the morning sort of thing but she is starting to do a few things for herself but I you know I

32

company
doing things with someone else
deliberate, not by accident
step by step - deal with it when it comes
enjoy where you're at
Got used to it - how it works
[illegible] expect
Not a big deal - once in a routine
progress
Starting to relieve some responsibility
able to let go a little
time off, time to refresh,
SHARING THE LOAD

Doing things together
Committing to increase stability post-discharge
Talking issues together
Feeling allowed and allowed
Enjoying time together again
Managing life step by step
Practical support from others
Sharing the load
Routine providing sense of safety and security
Creating routine
Reached a quick adjustment
Starting to relieve some responsibility

not the admission that helped her get better
Walking dogs together - spending time together
Dogs - more about creating opportunities to talk
Able to talk more openly when outside
BEING TOGETHER - a partnership, tackle problems together
working but at a time
less pressure being outside, opens up conversation, in the fresh air
Support from aunt
Aunt took pressure off, could take a break, indicates intensity of the situation
not alone
Importance of sleep
Cooked meals, gave medication
Coping - related to good sleep
There for the essentials - food
Got into a routine - suits me
once in a routine - ok
have [illegible] keeping her alive, level of dependency/ reliance
Adjusted to it quickly
once you have a structure, predictable, getting used to doing it, feeling ok about it, confident
Aunt's support made it easier - another pair of hands
Starting to do some things for herself



Transcript – Stephanie

don't want her to rush it and then get poorly again where she's done too much too quick and I think that's what her little blip was sort of thing so

I: The more recent

P: Time....yeah so it's taking each day as it comes I guess I have to keep reminding her she says it to me so it should apply to her too so yeah it's

I: And what was your sort of relationship like after she came....back

P: We've become a lot closer umm....she relies on me very heavily and I think she realises that umm basically like I I'm doing a lot for her sort of thing I'm like you'd do it for me I don't see it as you know she'd do it for me so I should do it for her sort of thing but she....you know I think we've become closer for it I think she appreciates me a little bit more....which is nice umm and I've noticed as well usually if she snaps she's right that's it sort of thing but now she's....you know if she has a little bit of a stress she apologises pretty much straight away so....we've come to understand each other a little bit more n she understands that I'm not a child anymore and she can talk to me about these things and I I will try and help her so....it is nice in that sort of way....I mean I look after most of her paperwork now I mean she does bits here and there which which worries me a little bit 'cos it's my dad's as well but I mean it is hers so I can't really stop her but it's nice that she asks me for help as well now so....I think it's good 'cos we're working together now to make things the way they should be so yeah

I: And if you looked back over the whole sort of discharge bit...what what was sort of unhelpful or helpful about about it

P: The nurses at *[hospital ward name]* like I said were very helpful umm the discharge like when she was actually coming home was quick and simple but the

not pushing it

trying to balance increasing independence but not doing too much too soon

not predicting future

opposite

private

practical arrangements ok

moral limitations

presence of dad - impact on dad - ways

moral issues around privacy boundaries etc - ways to us can't its hers

Balancing increasing independence and timing

Fear of mum doing too much too soon

Fear of a readmission

"Taking each day as it comes"

Living in the present moment

Feels appreciated

Doing what I ought to do

"We've become closer for it"

Have come to a shared understanding

She lets me in

~~[illegible]~~

~~[illegible]~~

Conflicted about issues of taking control and encouraging independence

Mum's rights vs. my fears.

Sense of partnership

Good communication

Aunt spent a lot of time here - unsociable hrs - diff from other teen perhaps

↓ extended family

Don't want her to rush it

Fears of relapse - big on knife edge

Pace is important - steady pace - moving is about doing everything quickly!

↓ back to encouraging her to sleep, relax, keep calm - when came home

Take each day as it comes

not to predict future,

living in the present moment

Relies on her heavily

Shows some appreciation / gratitude / understanding

Duty, responsibility, pay back - home

Become closer, appreciates what she does

Just doing what she ought to do - not resentful

helps transition

more able to regulate her emotions

relationship between mum + daughter

increased understanding, shared understanding

Feels more involved, more part of it, like she lets her in more [illegible] - not shielded anymore

worries about mum doing more for herself

more able to support her - in the loop - roles

↓

COMMUNICATION

working together, partnership

Fear of relieving duties, giving more independence

Nurses were helpful

Discharge - quick + simple

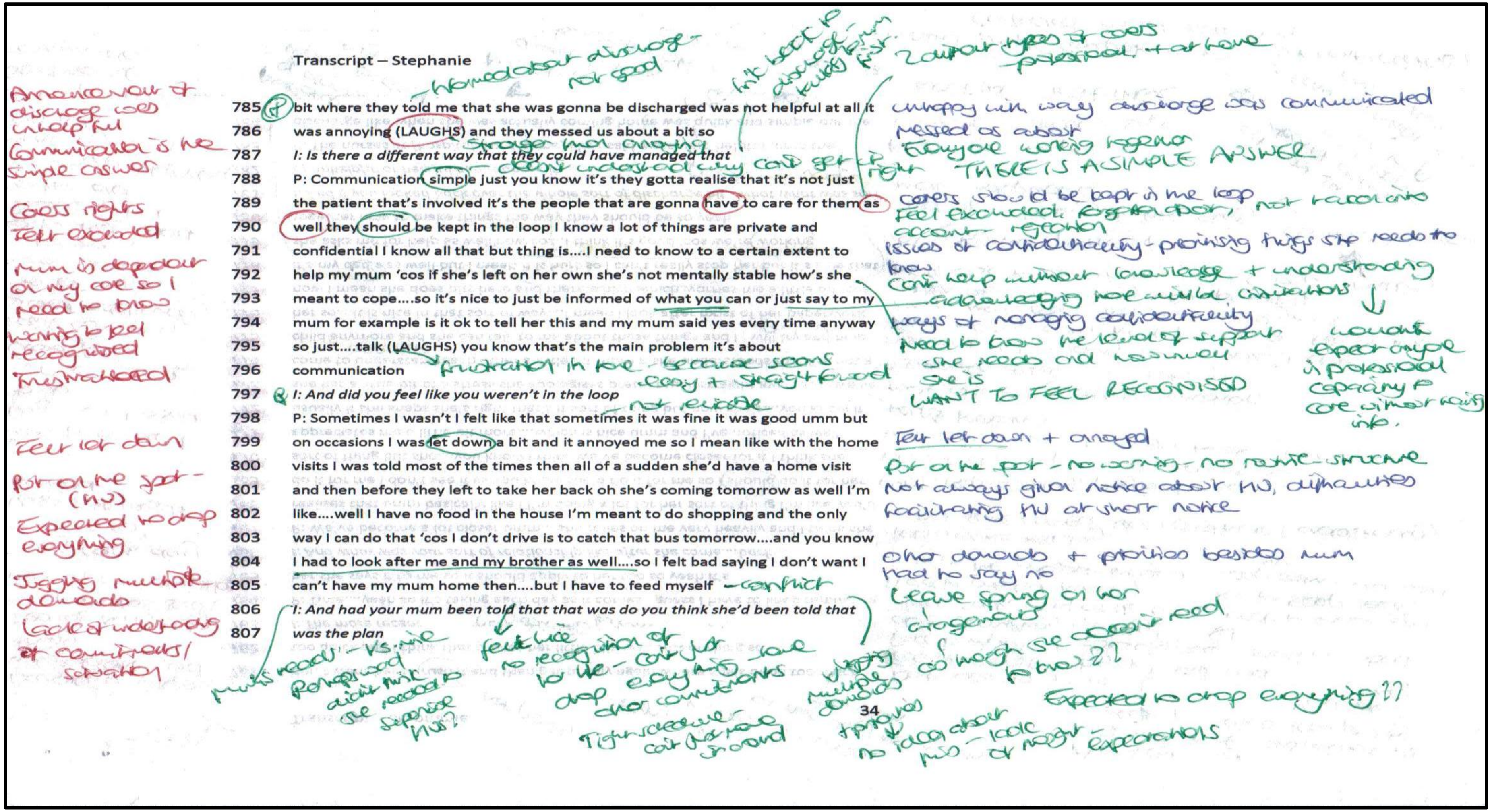
WORKING TOGETHER

at least she doesn't do things without keeping in the loop

- communication helps conflict

- would prefer complete control - (but contradictions)

conflicted around her idea



Transcript – Stephanie

bit where they told me that she was gonna be discharged was not helpful at all it was annoying (LAUGHS) and they messed us about a bit so

I: Is there a different way that they could have managed that

P: Communication simple just you know it's they gotta realise that it's not just the patient that's involved it's the people that are gonna have to care for them as well they should be kept in the loop I know a lot of things are private and confidential I know all that but thing is....I need to know to a certain extent to help my mum 'cos if she's left on her own she's not mentally stable how's she meant to cope....so it's nice to just be informed of what you can or just say to my mum for example is it ok to tell her this and my mum said yes every time anyway so just....talk (LAUGHS) you know that's the main problem it's about communication

I: And did you feel like you weren't in the loop

P: Sometimes I wasn't I felt like that sometimes it was fine it was good umm but on occasions I was let down a bit and it annoyed me so I mean like with the home visits I was told most of the times then all of a sudden she'd have a home visit and then before they left to take her back oh she's coming tomorrow as well I'm like....well I have no food in the house I'm meant to do shopping and the only way I can do that 'cos I don't drive is to catch that bus tomorrow....and you know I had to look after me and my brother as well....so I felt bad saying I don't want I can't have my mum home then....but I have to feed myself

I: And had your mum been told that that was do you think she'd been told that was the plan

34

Ambivalence of discharge was unhelpful

Communication is the simple answer

Carers rights

Felt excluded

mum is dependent on my care so I need to know

wanting to feel recognised

Frustrated

Felt let down

Put on the spot (HV)

Expected to drop everything

Juggling multiple demands

Lack of understanding of commitments/ situation

– Worried about discharge not good

hit back to discharge – being told first

stronger than annoying

doesn't understand why can't get it right

frustration in tone – because seems easy + straightforward

– not reliable

– conflict

2 different types of carers professional + at home

unhappy with way discharge was communicated

messed us about

Everyone working together

THERE IS A SIMPLE ANSWER

carers should be kept in the loop, not taken into account

Feel excluded, frustration, rejection

issues of confidentiality – providing things she needs to know

Can't help without knowledge + understanding

acknowledging the wider situations

ways of managing confidentiality

Need to know the level of support she needs and how unwell she is

WANT TO FEEL RECOGNISED

wouldn't expect anyone in professional capacity to care without having info.

Felt let down + annoyed

Put on the spot – no warning – no routine – structure

Not always given notice about HV, difficulties facilitating HV at short notice

other demands + priorities besides mum

had to say no

Leave sprung on her

dangerous

enough she doesn't need to know??

Expected to drop everything??

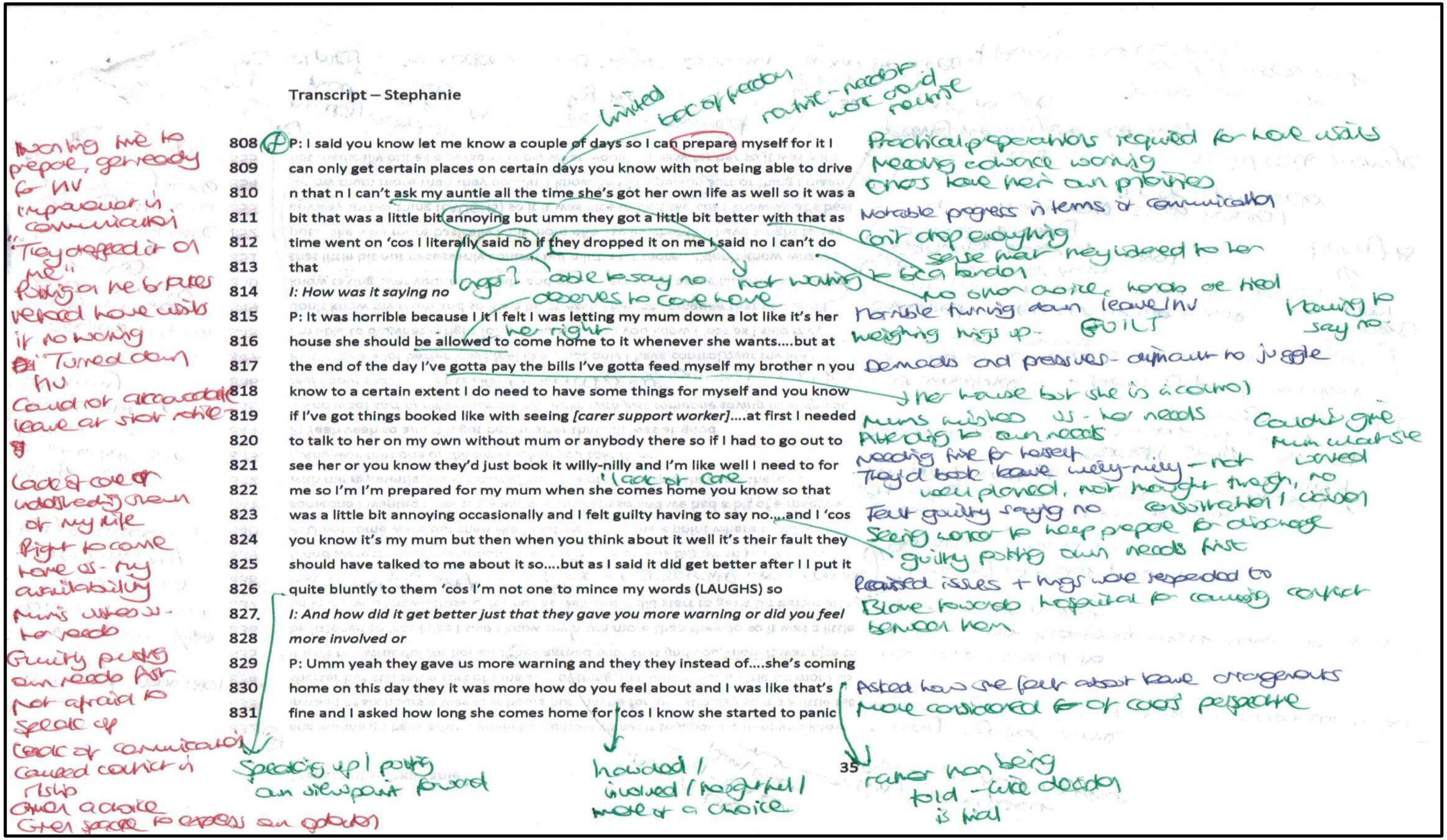
mum's needs vs. the professional didn't think she needed to be separate HV?

felt like no recognition of her – can't just drop everything – have other commitments

Tight schedule can't just move around

juggling multiple demands + priorities

no idea about HV – lack of insight – expectations



Transcript – Stephanie

P: I said you know let me know a couple of days so I can prepare myself for it I can only get certain places on certain days you know with not being able to drive n that n I can't ask my auntie all the time she's got her own life as well so it was a bit that was a little bit annoying but umm they got a little bit better with that as time went on 'cos I literally said no if they dropped it on me I said no I can't do that

I: How was it saying no

P: It was horrible because I it I felt I was letting my mum down a lot like it's her house she should be allowed to come home to it whenever she wants....but at the end of the day I've gotta pay the bills I've gotta feed myself my brother n you know to a certain extent I do need to have some things for myself and you know if I've got things booked like with seeing *[carer support worker]*....at first I needed to talk to her on my own without mum or anybody there so if I had to go out to see her or you know they'd just book it willy-nilly and I'm like well I need to for me so I'm I'm prepared for my mum when she comes home you know so that was a little bit annoying occasionally and I felt guilty having to say no....and I 'cos you know it's my mum but then when you think about it well it's their fault they should have talked to me about it so....but as I said it did get better after I I put it quite bluntly to them 'cos I'm not one to mince my words (LAUGHS) so

I: And how did it get better just that they gave you more warning or did you feel more involved or

P: Umm yeah they gave us more warning and they they instead of....she's coming home on this day they it was more how do you feel about and I was like that's fine and I asked how long she comes home for 'cos I know she started to panic

limited

lack of freedom

routine - needed
not avoid routine

agg?

able to say no

not wanting

deserves to come home

her right

'lack of care

Speaking up / putting
own viewpoint forward

Included /
involved / respectful /
more of a choice

Practical preparations required for home visits
Needing advance warning
Others have their own priorities
Notable progress in terms of communication
Can't drop everything
sense that they wanted to her
to be a burden
no other choice, needs are [illegible]
Horrible turning down leave/HV
weighing things up - GUILT
Having to
say no
Demands and pressures - difficult to juggle
her house but she is a control)
Mums wishes vs - her needs
Attending to own needs
Needing time for herself
They'd book leave willy-nilly - not
well planned, not thought through, no
consideration / caution
Couldn't give
mum what she
wanted
Felt guilty saying no
Seeing worker to keep prepare for discharge
guilty putting own needs first
Resolved issues + things were responded to
Blame towards hospital for causing conflict
between them
Asked how she felt about leave arrangements
More considered & of carers' perspective
rather than being
told - where decision
is final

Wanting time to
prepare, get ready
for HV
improvement in
communication
"They dropped it on
me"
Putting on the brakes
refused home visits
if no warning
"Turned down
HV
Could not accommodate
leave at short notice
Lack of care or
understanding
of my life
Right to come
home vs - my
availability
Mum's wishes vs -
her needs
Guilty putting
own needs first
not afraid to
speak up
Lack of communication
caused conflict in
rship
Given a choice
Given space to express own opinion

Appendix T

Summary table of connections between emergent themes

STEPHANIE			
Super-ordinate themes	**Subordinate themes**	**Subcategories of themes**	**Key words/phrases and reference**
Timing, timing, timing ***“I wanted it to be the right time” (21.486-487)***	**Home visits arranged at short notice** *“They dropped it on me”* *“Let me know a couple of days so I can prepare myself for it” (35.808)*	I was put on the spot	*“Before they left to take her back oh she’s coming tomorrow” (34.801)*
		Staff unaware of other demands and pressures	*“I have no food in the house I’m meant to do the shopping…only way I can do that…is to catch the bus tomorrow…I had to look after me and my brother as well” (34. 802-804)*
		No choice but to say ‘no’	*“I literally said no…I can’t do that” (35.812-813)*
		I felt guilty for prioritising own needs	*“It was horrible…I felt I was letting my mum down…it’s her house she should be allowed to come home to it whenever she wants…but at the end of the day I’ve gotta pay the bills I’ve gotta feed myself…to a certain extent I do need to have some things for myself” (35.815-818)* *“I felt guilty having to say no” (35.823)*
	Discharge announced out of the blue *“I was told pretty much last minute that she’d be coming home” (22.511-512)* *“It was quite sudden” (22.517)*	Completely taken aback and overwhelmed	*“It was a big shock to me” (23.531)* *“The shock of all of a sudden discharging…it was very quick” (25.576-577)*
		Feeling destabilised	*“I’m not ready for that”*
	I wanted her home but I needed time to brace myself *“I felt I was being really horrible not wanting*	Needing to gain strength prior to discharge	*“I just wanted to make sure I was strong enough” (24.562)*
		Saying no and suffering the consequences	*“So she wasn’t allowed to come home ‘till the next day so she called*

	to look after my mum that's not the case I wanted it to be the right time" (21.485-487) *"I wanted to sort of mentally prepare myself for her to be home" (22.524-525)* *"It's not that I don't want her to come home I just want it to be the good the right environment" (23.529-530)*		*me a bitch a cow all this" (23.534-535)* *"She called me a few names so obviously blamed me at first which is fair enough 'cos I'm the one that said no" (27. 632-634)*
		Needing to prepare for taking back responsibility	*"I just wanted to be in the right frame of mind 'cos if she's not someone needs to be for her" (24.563-564)* *"I just needed to come to terms with the fact that she's gonna be home it might be difficult for a bit" (28.642-643)*
		Needing time to organise support	*"It's just a case of making sure that things are in place where I could get help if I needed it" (24.570-571)*
Highs and lows in relationship with staff ***"That lady was very helpful…but other than that" (26. 609-610)***	**Feeling out of the loop vs. feeling involved** *"I need to know…to help my mum" (34. 791-792)*	Lack of discussion, shared decision making, liaison and negotiation	*"Just talk…that's the main problem it's about communication" (34. 785-796)* *"On occasions I was let down" (34. 799)*
		Reduced feelings of helplessness	*"Not only I have control over my life I'm able to do what is right for mum" (36.847-848)*
		My life was in their hands	*"It's a bit stressful having someone that you don't know taking over your*

			mum's life and effectively yours as well" (36.849-850)
	Feeling undervalued and not recognised *"It's not just the patient that's involved it's the people that are gonna have to care for them" (34. 788-789*	Lack of empathy and understanding	*"They'd just book it willy-nilly" (35.821)*
		Expert knowledge denied	*"I just said you don't know my mum so ask me in future" (25.587-588)* *"I know what's best for my mum more than they do…know her as a person" (36.853-854)*
	Receiving support in my hour of need	There was someone on my side	*"There was a very nice lady…and we had a discussion…she was quite supportive" (26. 597-600)*
		Taking the pressure off	*"As soon as I said that that lady come in and straight away said she's not ready for it she's not going home today" (26.607-608)*
Fearing discharge	**Distressing times on leave** *"It was really quite upsetting" (20.465-466)* *"They started with an overnight stay and that didn't work very well" (21.495-496)*	Mum behaving out of character	*"She went tachycardic and went all funny it was as if she had a stroke…she threw herself off the bed and I had to try and pick her up" (20.456-460)* *"She just didn't sleep and she was still very hyper" (21.499)*
		Feeling helpless	*"She cried it was wailing it wasn't just little tears it was uncontrollable" (21.500-501)*
		Feeling rejected	*"She would be at home and then she would actually want to go back [to hospital]" (22.504-505)*
		Upsetting memories endure	*"I wanted it to be the right time 'cos when they were trying before it*

			wasn't right and it was really bad" (21.483-484) *"Some of the home visits were quite disturbing" (28. 654)*
	Self-doubt *"She's gonna think she can't look after me" (28. 659-660)*	Uncertainty about own inner strength	*"I have to be the strong person in it all…that worries me 'cos if I get upset it's gonna upset mum and she's gonna think…she can't look after me" (28.657-662)*
		Pressure of being the glue that sticks everything together	*"More of me having to hold it together for everybody" (28. 656-657)*
	Responsibility for preventing readmission	Fearful of readmission	*"She's so scared of having to go back in there…I wanted to make sure I was strong enough" (24.561-562)*
		I need to do my job properly to prevent readmission	*"Being in the right frame of mind and being prepared in case she had a bad bout again" (24.560-561)*
Having to adjust to a new way of life ***"It was a big shock at first 'cos…from one thing to another it's a big change" (29.682-683)***	**Discharge signalling start of a new chapter** *"It's like having a baby" (28.648-649)*	Leaving independent life behind	*"From being quite independent doing what I like have my own job" (27.638-639)*
		I gave up my life	*"Have to…give everything up basically" (27.639-640)*
	From daughter to parent *"It's just role reversal for a while" (28.662-663)*	Being a container	*"When she first came out of hospital I literally had to sit with her while she had a shower and she asked me if she was doing it right…she gets very panicky" (9.191-194)*
		Providing reassurance	*"I just try and encourage her that there is a point in her being here" (9.205-206)*
		Determining the rules and setting	*"I tried to set up a new routine …I*

		boundaries	*said you know you’re not allowed to get out of bed ‘till nine” (30.699-701)*
		Looking after the house	*“I basically do everything round the house I clean the house…I cook” (11.250-253)*
A hopeful yet challenging aftermath	**Increased sense of togetherness but some residual doubts** *“We’ve become closer for it” (33.770)*	Enjoying time together again	*“We try and make a point of walking the dogs together…we’re enjoying it together” (32.738-739 & 742)*
		Tackling issues together	*“I think it’s good ‘cos we’re working together now to make things the way they should be” (33.779-780)*
		She lets me in	*“She understands that I’m not a child anymore…she asks me for help” (33.774-775 &779)*

Appendix U

Example of a master table for one super-ordinate theme

'Getting back on track'

Participants	Subordinate themes	Participants	Key cross-references	Indicative quotes	Notes
All except Elaine	Developing structure and routine	Stephanie, Helen, Brenda, Dianne, Margaret	Stephanie (L191, 699, 751), Helen (L521, 537, 835), Brenda (L601), Dianne (L243,1666), Margaret (L648, 664, 668, 683)	"I tried to set up a new routine…I said…you're not allowed to get out of bed 'till nine…to give her some sort of structure…she sticks to it now…things are getting a lot better with things like that" (Stephanie, L699) "I've gotta keep her going and active you know because she's gonna get bored and I don't want her…ever…to go back to…having a drink you see" (Dianne, L1666)	Elaine is a counter-case here. This is perhaps because she does not have daily contact with her relative like the other family members, and also her sister has had more admissions, compared to others. Margaret clearly valued structure and routine like the other carers but didn't instigate it herself because this was achieved by the package of support in place upon discharge. Brenda described mental illness as a 'taboo' in her house. Once her son was home, it seemed everyone just tried to 'forget' what happened rather than behaving any differently, like other carers. It is as though she coped by 'sealing over.'
	Rebuilding relationships	Stephanie, Helen, Brenda, Dianne, Margaret	Stephanie (L720, 770, 779), Helen (L303, 490, 818, 1036, 1048), Brenda (L311, 320), Margaret (L957, 1394)	"Her personality is coming through a bit more…we've become closer for it…we try and make a point of walking the dogs together…we're enjoying it together" (Stephanie, L720) "We have worked through it" (Helen, L490)	All participants except Elaine described a sense of renewed togetherness in their relationship with their relative after discharge. Elaine was markedly more angry and frustrated with her relative and described their relationship as more fractious, tense and fragile compared to the other family members.

Appendix V

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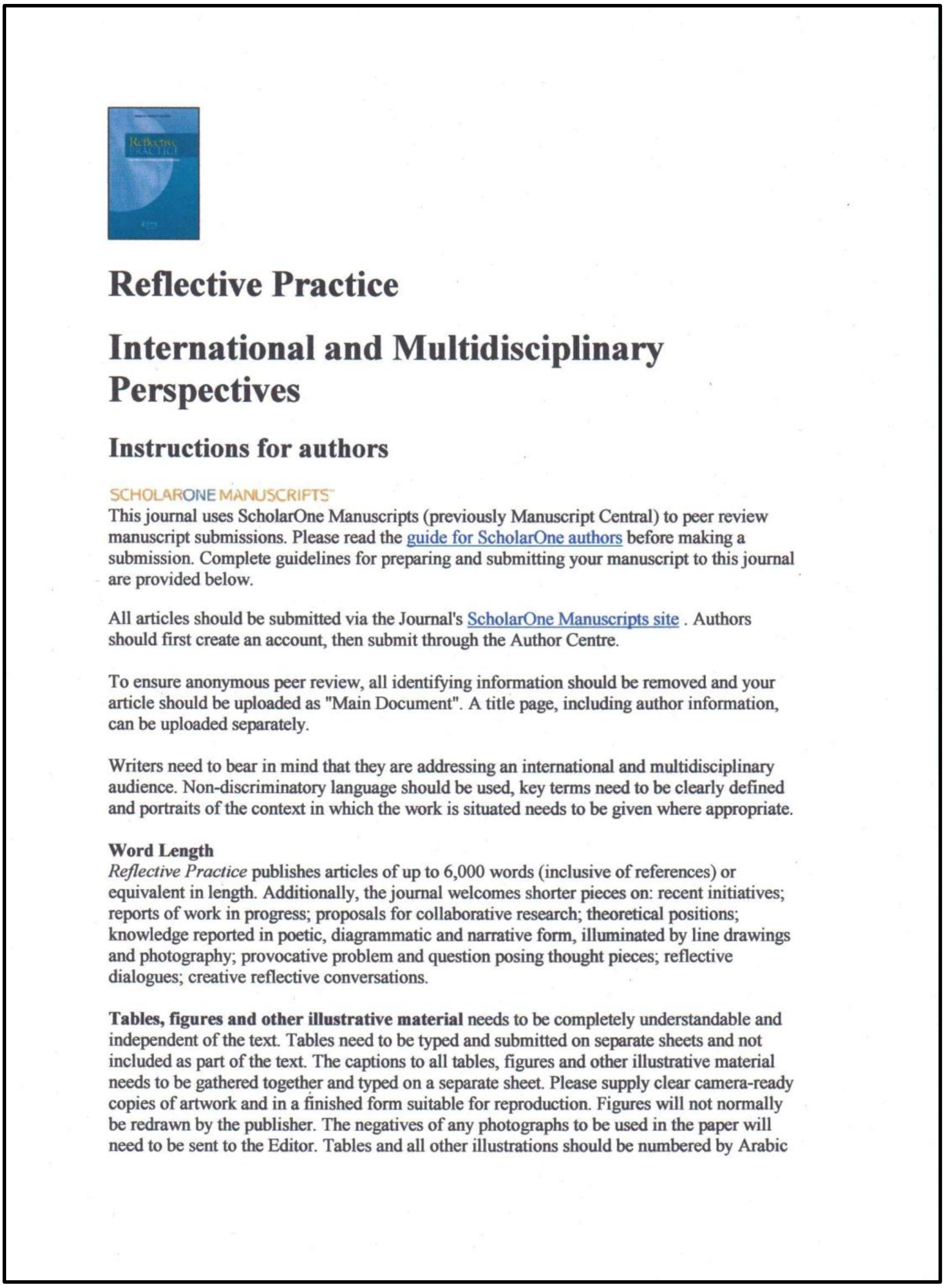

Reflective Practice

International and Multidisciplinary Perspectives

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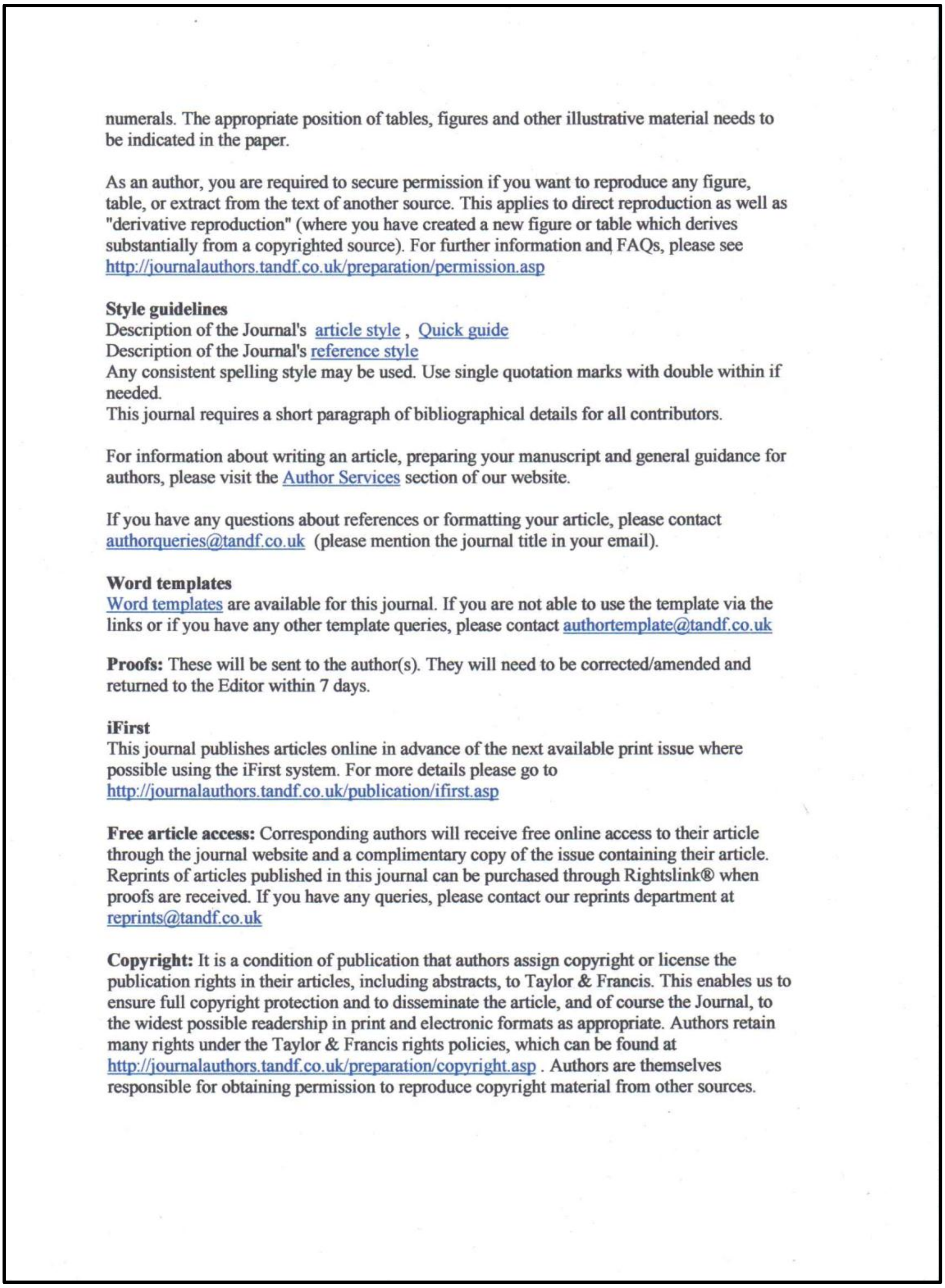

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