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Knitting with my mother: Using interpretative phenomenological analysis and video to investigate the lived experience of dyadic crafting in dementia care

Mah Rana Birkbeck, University of London

Jonathan A. Smith Birkbeck, University of London ja.smith@bbk.ac.uk

Abstract

This article presents findings of a Ph.D. case study that uses interpretative phenomenological analysis (IPA) to elicit a deep understanding of lived experience within the context of a 'craft-encounter' shared by an adult carer with her mother, who has dementia. Recent studies have evaluated the health and well-being benefits of participatory craft practice in community-based projects. However, a less examined site of research is the lived experience of participating in shared craft-encounters as a domiciliary based intervention for dementia care. This study elicits a nuanced understanding of lived experience of participatory textile-based craft and explores the value of working with video as an adjunct to IPA's existing methodology as a way of attending to non-textual communication that is easily missed in the moment of occurrence. Reviewing primary-source video with participants produces additional data as a result of participants' reflexivity and meaning-making through interpretation of video footage. The findings challenge the dominant bias that frames dementia care only

in terms of losses without considering the potential gains and meanings of the dementia care experience.

Keywords: craft, knitting, interpretative phenomenological analysis, dementia, mother-adult daughter dyad, video, dementia care, domiciliary intervention

The research context

Recent dementia and aging studies highlight the health benefits of crafting as mentally stimulating activity (Geda et al. 2011; Phinney et al. 2007), and as a provider of multisensory triggers in reminiscing activities to buffer against the effects of dementia (Brooker and Duce 2000; Pöllänen and Hirsimäki 2014).

As one of the top ten causes of death, dementia cannot be prevented or cured. Dementia diagnoses are set to rise to 1 million in the United Kingdom by 2021 (Brown 2017). Increasingly, more attention is being given to the value of participatory craft practice as part of dementia care to support good psychological health and well-being. This has been studied and evidenced across different disciplines within hospitals, care organizations and community projects to meet the needs of different stakeholders including patients, carers, health professionals and community support workers (Brooker and Duce 2000; Fletcher and Eckberg 2014; Pöllänen and Hirsimäki 2014). In parallel, limited resources in residential elderly care provision in the public sector, and high costs in the private sector, are increasingly pushing families and individuals towards organizing and self-managing non-clinical care. Textile-based craft activities, such as knitting and embroidery, can be scaled to suit individual needs and capabilities and delivered at minimal cost within home environments. Dementia not only affects the

person diagnosed; it impacts significantly on informal caregivers' well-being. Whilst there have been studies that support the use of craft-engagement as a model to improve well-being for people diagnosed with dementia (Brooker and Duce 2000; Pöllänen and Hirsimäki 2014), there is a strong argument to broaden this field of research to explore relational aspects of crafting within the context of the dementia-caregiver dyad at home. A dyad is a pairing of two individuals in an interpersonal situation; a dementia-caregiver dyad is a person with dementia and their caregiver. To date, dyadic crafting, as part of domiciliary dementia care, remains an unexamined site of research.

Whilst theoretical literature and clinical studies tend to focus on the dementia-caregiver dyad in terms of caregiver burden, guilt and compassion fatigue; psychosocial outcomes of craft practice have predominantly been discussed in contexts of subjective well-being (Reynolds et al. 2008; Tzanidaki and Reynolds 2011), and psychological well-being (Burt and Atkinson 2012. Riley et al. (2013) refer to 'social well-being' as a craft-process outcome without ascribing it to a specific theoretical well-being model, however 'social well-being' aligns with White (2015) who argues for a 'relational well-being' theoretical model that posits well-being as shaped by intra- and interpersonal processes influenced by cultural contexts and social processes.

This article presents a Ph.D. case study that is conducted within a psychological sciences context. Through the researcher's interpretation of the study's participant account of their lived experience, the presentation of study data highlights the value of using shared craft-encounters as a domiciliary based intervention for dementia-

caregiver dyads and broadens psychological understanding and insight into relational aspects of crafting as a social process.

Design of the study

IPA is a psychological qualitative approach, developed in the 1990s by Smith (1996), to the study of meaning-making drawn from lived experience of a given phenomenon (Smith et al. 2009). The scope of IPA research covers, but is not limited to, health and illness, identity, sex and sexuality and psychological distress. Study topics include, for example, the experience of psychosis and early intervention (Latif et al. 2004), female anger-related aggression (Eatough and Smith 2006), identity and motherhood (Smith 1999). The semi-structured interview is one method available to elicit first-person accounts, thoughts and feelings of an individual's lived experience (Langdridge 2007). However, this method heavily relies on audio to provide data material, leaving the body as a sense-making subject not fully accounted for.

Therefore, this IPA study proposes to use video to record the sequential organization and unfolding of socially mediated and embodied interaction *in situ*. Video's audio-visual and temporal properties enable the study of non-linguistic knowledge and embodied aspects of lived experience that would otherwise remain inaccessible to the researcher (Mondada 2008; Toraldo et al. 2018), however, this IPA study uses primary-source video footage also as an aide memoire to enable participants to reflect on social interaction that they have engaged in. Whilst the participant is still acknowledged as an expert of their situation (Smith et al. 2009), video footage enables

events, and intra- and interpersonal behaviour to be foregrounded and enlarged that would otherwise be hidden or not recalled. This enables the study phenomenon to be examined in the social context in which it occurred, with non-textual communication attended to – such as embodiment and multisensory elements (Forsyth et al. 2009).

Hermeneutics, as applied to IPA, is concerned with interpretation and meaning-making. Therefore, consistent with IPA's phenomenological and hermeneutic theoretical underpinnings the study craft-encounter was designed to facilitate a mother and daughter's engagement with textile-based crafting from which the daughter's detailed first-person account of lived experience could be elicited and interpreted. The study did not focus on dyads with an existing shared craft practice, but rather on a shared craft-encounter that was set up as an intervention in order to investigate the potential of such a strategy as a form of domiciliary dementia care.

The term 'double hermeneutic' is used to emphasize the two interpretations present in IPA's methodology: the first is the participant's meaning-making resulting from their interpretation of personal experience, the second is the researcher's sense-making resulting from their interpretation of the participant's account (Smith et al. 2009). The researcher must apply a reflexive approach towards sense-making in their interpretation, thus mirroring the participants' active role in the study (Shinebourne 2011). IPA follows an idiographic approach, analysing detailed accounts of an identified phenomenon as experienced by a small group of purposively sampled individuals (Langdrige 2007). The most common dementia-caregiver dyad in 'developed countries'

is mother and adult daughter (Messinger-Rapport et al. 2006), hence the use of this dyad type in the study.

The craft-encounter

The case study involved an adult daughter and her mother who has dementia. The daughter is pseudonymously called Diane (a name chosen because it shares its first letter with the word daughter); the mother is pseudonymously called Mary (a name chosen because it shares its first letter with the word mother). The dyad was recruited from a local authority day-centre where Mary is an attendee. Mary taught Diane as a child to knit, but since then they have not knitted together; both gave written consent.

Diane chose knitting as the craft-encounter, which took place in the dyad's living room. Diane and Mary used their own knitting needles and yarn. A tripod-mounted DSLR camera was used to video the craft-encounter and social interaction. Faces were included in the recording because the study sought to explore how video data can be used to investigate an embodied creativity framework of body-subject, body-object and materiality. This included observing how an integration of semiotic practices and resources shapes social, embodied and material interaction and meaning-making *in situ*. While the dyad was engaged in the craft-encounter the researcher waited in another room; this set-up was designed to maintain the dyadic relationship.

Two days after videoing the craft-encounter the researcher returned to the participants' home to conduct a semi-structured interview with the daughter only. The interview was conducted in two parts. For the first part, consistent with IPA's

methodology, a list of open-ended questions was used as a prompt to elicit from Diane her own account of her experience of the phenomenon, i.e. knitting with Mary. For the second part of the interview the unedited video footage from the previous visit was watched in chronological order of recording and Diane was asked to signal 'pause-playback' if she saw something of interest she wished to comment on. Primary-source video footage acts as an aide memoire because subtle details of verbal and visual communication and embodied action are easily missed or overlooked in the course of organizational interaction. Reviewing video playback of the study phenomenon allowed Diane to reflect on her own intersubjective embodied experiences, and the embodied experiences of Mary. The interview was audio-recorded and transcribed verbatim.

Analysis

The final analysis is presented as a narrative using the themes to provide a compelling account for the reader of key experiential outcomes of the study.

The analysis explores how Diane's sense-making of her lived experience of knitting with Mary enables her to recapture and reconfigure past experiences. Attention is given to Diane's account of the challenges she faces by both knitting with and caring for Mary. By deepening an understanding of the participant's experience, the analysis also explores the psychological shift in Diane's cognitive response to Mary's knit performance, and how a change in the dynamics of interpersonal communication culminates in creative and reciprocal acts.

The IPA data analysis followed steps as outlined in Smith et al. (2009). The transcribed audio recording was read, with exploratory comments written in the margins. These exploratory comments were collated together into meaningful aggregations to form emergent themes. Emergent themes were grouped in clusters. Each cluster was assigned under a super-ordinate with a descriptive label corresponding to its conceptual attribution. This was followed by a detailed descriptive account of each of the super-ordinates that led to an outcome that is a synthesis of a psychological interpretive account of the lived experience of the participant. The analysis was summarized and illustrated with interview extracts as part of the final narrative account of the study phenomenon.

A detailed analysis of the transcript allowed four super-ordinate themes with accompanying emergent themes to come to the fore, offering a rich and nuanced account of Diane's experience of knitting with Mary.

Super-ordinate themes

1. Relinquishing perceived control
2. Craft as skilled activity
3. Observations of behaviour
4. Craft as self-expression

For this article, the first super-ordinate theme is discussed; see Table 1.

Table 1: Super-ordinate theme 1: Relinquishing perceived control.

Emergent themes	Illustrative key phrase from recorded interview
Personal interests compete against an other's priority	'You didn't know what you'd done wrong. She was always too busy to pick up the bits and things like that.'
Letting go of control creates insight	'Oh, you just slip it over with your thumb.'
Control as a characteristic of flow	'She's gone into her own [...] you know, she's gone in.'

Findings

Personal interests compete against an other's priority

Control is an important coping strategy to make it possible for Diane to have Mary living in her home:

That's where the controlling comes from, because erm, the only way it works that she's here is if I have routines in place.

But that's me trying to control her, erm, so, [pause] she is not somebody to be controlled. And I mean, I can't, I can't work with her, because I don't know what, where, where she's thinking.

Diane is acutely aware of the inevitable set-up for failure in trying to control someone who does not want to be controlled:

She doesn't like following instructions actually; she would want her own instructions.

Tension with Mary permeates Diane's narrative:

We don't knit together, as a rule.

For 60 years Diane has adhered to this self-imposed rule and breaking it is a cause of anxiety. Diane's management of expectations and conflict permeates her talk:

Oh well I always thought, you might have sensed the tension, I had already thought this is not going to be easy. I'm not sure I'm going to enjoy this [knitting with Mary].

Diane's unease is understandable based on her recollections of early childhood experiences of knitting with Mary, and competing for attention:

As a little girl I can remember knitting these little bits and then I would [...] they would come out misshapen because you'd drop a stitch, and you didn't know what you'd done wrong. She was always too busy to pick up the bits and things like that.

References to the self as novice to another's expertise, and motivation, are explored to understand Diane's incentive to override her rule of not knitting with Mary:

I was always intrigued by the way she managed to keep, instead of having to keep dropping the wool to pick up the other one [wool], she keeps it in the two [hands].

That's what's always fascinated me, is how she's kept one bit of wool in one hand and one [in the other hand] [...] and that's what I've been *trying* to find out.

Unsuccessful *trying* seems to add leverage to Diane's motivation for rule-breaking to reach for something long-desired from Mary. For the study's craft-encounter Diane had asked Mary to teach her the technique for stranded knitting. Stranded knitting uses two or more colours to create patterns associated with Fair Isle and Nordic knitwear. Before her dementia diagnosis Mary often used the stranded technique to knit with two colours of wool. During the study's craft-encounter, Diane notices that Mary employs a special trick, which for the purpose of this article will be referred to as the 'knit-trick', allowing her to knit with yarn from a ball of wool held in one hand while simultaneously holding yarn from a second ball of wool in the other hand, enabling her to execute stranded knitting at speed. Diane is keen for Mary to teach her this 'knit-trick', however,

Mary's fixed focus on her own work disrupts interpersonal communication and contributes to the breakdown of the interaction; Diane's goal appears to be lost.

Diane's experience of this interactional turn risks reinforcing her original conviction that their knitting-together relationship has been and still is a source of tension:

Well, I *just* didn't think we were getting *anywhere*, I *just* thought this isn't actually *got to* what I wanted to achieve.

Diane's tone of voice and use of 'just' as a discourse marker underpins the frustration in her self-talk. Even though footage of Diane and Mary shows a lot of action, there is little movement forward for Diane towards her goal, and she is left behind Mary:

I thought 'Let me try and catch up, get to the end of this row', so that I can get to, get to where she is, cause she'd gone forging off ahead.

Letting go of control creates insight

Due to a technical issue with the camera, the researcher entered the living room halfway during the craft-encounter, and in doing so their presence becomes a powerful mediator of the dyadic interaction. Diane engages in dialogue with the researcher and this temporary shift in the interpersonal dynamic allows Diane to relinquish her control of the craft-encounter and to step back from managing Mary's performance. As a consequence of relinquishing control, Diane achieves her goal of learning Mary's knit-trick. The temporal references are explored in this extract of the interview where Diane is commenting on having just watched a short excerpt of video footage. Diane begins in the past tense:

I didn't get a chance to see until she was doing it there, and that's when I had the *revelation*, I was going 'Oh, you just slip it over with your thumb. You keep it over there and then you just slip it round, and pull the needle through, yeah'. Instead of doing what we're used to doing because it's on that side she just hooks [with her thumb], yeah.

The shift from past tense to present tense perhaps represents a connection between the hoped-for outcome and reality experienced by Diane, even though the reveal of the knit-trick was only after the mother-adult daughter dyad had changed to a triad of mother-adult daughter-researcher. Diane's use of 'revelation' could be considered as overly dramatic, but arguably it shows how important it has been for Diane to learn Mary's knit-trick. A trick that has eluded her for years, invisible to her untutored eye, has suddenly become clear in the manner of something once regarded as unattainable and complex becoming attainable and simple.

Control as a characteristic of Flow: Dependent to agentic

After watching more of the video footage, there is a reverence in the way Diane talks about her experience of watching Mary knitting:

You can see now how she's clearly, *it's come back to her*. She's, you know, that's why *I'm relaxing*. It's actually come back to her, she knows what she's doing. Yeah. Because she's gone into her own [...] you know, she's gone in, it's, she's just, [inhales softly and speaks quietly] Oh God, I don't know what it is, I just know, that she's, erm, the speed at which she doing it, the body language, the way she's, you know, she's kinda like sitting back, she's not, she doesn't look *temporary* about it.

Her hesitancy and somatic response reinforce the significance of the resurrection of the agentic mother that she is trying to describe. When Diane says *it's com[ing] back to her*

one can imagine this as another revelation as she watches Mary's embodied memories come back, perhaps even the disbelief of seeing Mary as she was before the dementia diagnosis; as if witnessing the past revealed in the present:

She doesn't look temporary about it.

That's why I'm relaxing.

The temporal reference alludes to a psychological shift in Diane's understanding from seeing Mary in a new light; a mother who is not stuck. Perhaps Diane dares to believe that Mary's agency will continue, and the stress that accompanies Diane's control-as-coping as a carer will ease:

It wasn't that I was anti my mum, but I was the, I kinda was *least drawn* to her. Which is why it's really weird that she ends up living with me [laughs].

It drew me in. It drew me in to [...] actually we're not being as we would have been when we were younger. We're not being, we're not fighting each other.

To understand Diane's psychological state of mind it is interesting to explore how she uses the verb 'to draw' in talk about emotional bonding and reflecting on the experience of knitting together. The use of *least drawn* and *drew me in* perhaps illustrates Diane's emotional connection as a psychological shift from one place to another, from being on the outside to now being closer to Mary.

Rooted in the experience of crafting together, Diane can perhaps conceptualize an alternative future mother-and-daughter dynamic, albeit perhaps one she could not have had without Mary having dementia.

Discussion

This reflective case study has looked at nuanced meaning-making and identity from the perspective of an adult daughter dementia carer. With the rise of individuals being diagnosed with dementia, intergenerational caregiving between persons with dementia and family members will become increasingly common; the most common dementia-caregiver dyad is the mother-adult daughter dyad (Messinger-Rapport et al. 2006).

As well as pointing to the therapeutic potential of craft, current literature highlights the relational context of crafting as a social process (Pöllänen 2009; Reynolds et al. 2008; Pöllänen 2015; Howie et al. 2004; Riley et al. 2013). This relational aspect underpins caregiving relationships that are shaped by past and present experiences (Poirier and Ayres 2002 cited in Ward-Griffin et al. 2007).

Diane's account of her caring for Mary maps with the Custodial Mother-Daughter Relationship: a dementia care model which focuses more on routinized care and less on emotional support (Ward-Griffin et al. 2007). But it is argued that the phenomenon of knitting together, as a psychosocial intervention, was powerful enough to mediate a psychological shift for Diane, enabling her to re-imagine her future caregiving closer to a Cohesive Mother-Daughter Relationship: a dementia care model that focuses on a mother's strengths and need for agency (Ward-Griffin et al. 2007).

After an early disruption during the study phenomenon Diane, finally, was able to get to the knit-trick that was her outwardly expressed goal. Ultimately, taking part in the study could be reframed as a way for Diane to get closer to Mary, albeit through a circuitous route.

Current dementia and creative engagement research frames crafting as potentially relational, in that caregivers may indirectly benefit from the increased well-being experienced by persons cared for (Fletcher and Eckberg 2014), however, an interpretation of Diane's experience and meaning-making points to the possibility of framing crafting as explicitly relational and consequently effecting psychological change. In addition, Gauntlett (2011) argues that dimensions of happiness are drivers for individuals' search for social relationships through creativity; however, Diane's unique account offers an alternative nuanced and complex understanding of how crafting together can reconnect a relationship that was psychologically detached.

At the beginning of the craft-encounter Diane had spoken about how knitting with Mary was usually stressful. Diane's account of Mary being too busy to help her as a young child suggests that perhaps Diane had learnt from an early age that Mary is not going to help her; Diane, as a child, might have internalized this behaviour as neglect. However, Diane appears to be keen to take part in the study and this chimes with current literature that argues that a child with a parent who does not attend to their psychological needs might either retreat into themselves, or constantly strive for the parent's attention by pleasing them (Klein 1999). Diane is bemused by the irony that even though, as one of five siblings, she was the child least drawn to Mary; Mary ends up living with her. Perhaps, Diane's account of Mary's distant parenting style hints at Diane's motivation to join the study; it could be argued that joining the study was done in a continual effort to please Mary, and Diane's laugh that accompanied her bemusement perhaps minimized something that she recognized in her talk.

One could summarize that perhaps, throughout childhood and into adulthood, Diane had hoped that Mary's emotional distance would change. However, the desire for change was lost with the onset of Mary's dementia. The opportunity to take part in this study perhaps reinstated a glimmer of hope that taking part in something 'academic and scientific' might enable Diane to get closer to Mary, even though her motivation was expressed outwardly as wanting to learn Mary's knit-trick. So, when Diane describes how she and Mary are 'not fighting each other' she seems to be describing a shift in the way of relating that also relates across time. By reflecting on their past relationship and the present day she is able to notice a significant shift that perhaps, for Diane, is both unexpected as well as a long time coming.

As a case study for a larger Ph.D. research project, the study showed that the shared craft-encounter was a highly meaningful experience for Diane and highlighted potential for the shared craft-encounter as a valuable self-directed domiciliary dementia care strategy. By crafting together, Diane is drawn into Mary's world: a world from which one imagines that she had previously been excluded. Ironically, the hoped-for closeness that was quietly achieved was due to an illness that is usually perceived to alienate.

Methodological reflections

In methodological terms, the study demonstrates how video data can be a valuable and rewarding adjunct to IPA. Video data generation as part of fieldwork is a powerful method to record and review embodied interactions and situated activity in close

proximity (Knoblauch and Schnettler 2012). Reviewing primary-source video footage allows participants to reflect on their own intersubjective embodied experiences and also on the embodied experiences of others.

At the same time as acknowledging the value of using video as an adjunct to IPA, one must also accept the additional layer of complexity this adds to the methodology. As such, this study is not only about crafting and social making; it is also about the videoing of crafting, and complex textual analysis. It is this complexity that challenges the researcher in the undertaking and completion of the study, but it is also an opportunity for a more nuanced understanding of the study phenomenon. The potential for including a detailed analysis of the video material as part of IPA deserves further study.

Domiciliary dementia care is typically a private and intimate relationship between carer and the person being cared for: therefore, the addition of a camera in the research site requires sensitive management, and a commitment to the participants as collaborators. Recruitment for the study was difficult due to the visual component of the fieldwork. Several carers and gatekeepers of potential participating dyads expressed unease about videoing in the home and indicated a preference for participation if videoing took place in a community setting.

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