

‘My relationships have changed because I’ve changed’: biographical disruption, personal relationships and the formation of an early menopausal subjectivity

Kate Johnston-Ataata¹ , Jacinthe Flore¹ ,
Renata Kokanović¹ , Martha Hickey² ,
Helena Teede³ , Jacqueline A Boyle³  and
Amanda Vincent³ 

¹*Social and Global Studies Centre, RMIT University, Melbourne, VIC, Australia*

²*Department of Obstetrics and Gynaecology, University of Melbourne, Melbourne, VIC, Australia*

³*Monash Centre for Health Research and Implementation, Monash University, Melbourne, VIC, Australia*

Abstract Early menopause (EM) or premature ovarian insufficiency (POI) can disrupt gendered and age-related expectations associated with perceived ‘normative’ biographies for young adult women, with implications for subjectivity and relationships. While previous qualitative research has concentrated on the impacts of EM/POI on biography and sense of self, in this article, we examine the enmeshment of personal relationships with the formation of early menopausal subjectivities. Drawing on research exploring concepts of ‘biographical disruption’ and personal relationships, and theoretical work on social norms and subject formation, we present findings from a narrative thematic analysis of 25 interviews with women diagnosed with spontaneous or medically induced EM/POI. We identify three main narrative ‘types’ of subjective and relational experience in response to the ‘disruption’ of EM/POI: interlude and continuity; disruption and adaptation; and disruption and ambivalence. Women’s accounts of their experience of EM/POI indicate that the formation of early menopausal selves is mediated by the extent to which women and those around them identify with gendered norms related to reproduction and age. Consistent with theoretical perspectives that consider the self as relationally produced, we argue that the subjective and relational dimensions of EM/POI are intertwined and must be understood in tandem.

Keywords: menopause, reproductive health, subjectivity, interviewing (qualitative), experience of illness, women’s health

Introduction

Early menopause (EM) or premature ovarian insufficiency (POI) can introduce profound transformations to a woman’s health, emotional wellbeing and sense of self (Boughton 2002,

Orshan *et al.* 2001, Singer 2012). While the usual age of menopause is between 45 and 55 years, menopause before age 45 is considered early, and POI refers to the loss of ovarian activity before age 40. EM/POI may occur spontaneously or be medically induced (ESHRE 2016)¹. Embodied and affective changes women commonly experience include hot flushes, night sweats, reduced enjoyment of sex, emotional distress and long-term health implications including osteoporosis and heart disease (Shuster *et al.* 2010). To ease these impacts, women with EM/POI are advised to take menopausal hormone therapy (MHT) until age 50² together with lifestyle changes (ESHRE 2016).

EM/POI can also challenge women's 'gendered personhood' (Hampshire *et al.* 2012: 1045) due to fertility loss, a sense of 'premature' ageing and impacts on intimacy (Parton *et al.* 2017) and/or disrupt perceived normative life course expectations (Knobf 2008). In contrast to these potential impacts on subjectivity, the interlinked implications of EM/POI for women's personal relationships have received less attention. Yet disruptive life course experiences can affect one's personal relationships and sense of self in complex and interrelated ways (e.g. Becker 1997, Bury 1982, Ketokivi 2008). In this article, we aim to address this lacuna in the qualitative literature on EM/POI. Drawing on narrative interviews with women diagnosed with EM/POI living in Australia, we investigate the discrepant ways in which women's relationships are implicated in the formation of an early menopausal subjectivity.

To examine subjectivity necessitates consideration of how it is produced and transformed 'within wider socio-political and cultural elements and relations of power' (Kokanović and Flore 2017: 330). Consistent with our focus on personal relationships, we understand subjectivity as dependent on both 'complex material, discursive and relational influences' tied to time and place, and 'dynamic, intersubjective, unconscious processes' (Hollway 2006: 466). Thus, the subjective implications of EM/POI are both connected to 'larger' entities such as institutions and social norms and experienced through relationships with other 'subjects'; the focus of this article. We begin by reviewing the limited qualitative literature on experiences of EM/POI, focusing on findings related to its subjective and relational implications. We then present a conceptual framework for thinking through the interconnections between these dimensions found in women's accounts of EM/POI.

Literature review

Sociocultural and technological change is driving transformations in patterns of personal and family life, with an increasing proportion of people delaying or foregoing partnering and/or parenthood or creating families in new ways (Latimer and Thomas 2017). Nonetheless, cultural discourses portraying life as an 'ordered, continuous whole' (Becker 1997: 61) comprising sequential (loosely defined) 'phases' and associated social and familial roles remain salient for many, in turn shaping 'biographical expectations' (Bury 1982). A recurrent finding in the qualitative literature on experiences of EM/POI, based predominantly on research conducted among women living in the Global North, is that it frequently disrupts expectations of how life 'should' unfold. Many women describe a sense of loss in relation to 'life goals' (Boughton and Halliday 2008: 570) such as childbearing, career progression or financial plans (Anderson *et al.* 2011), or a perception of 'accelerated' ageing (Parton *et al.* 2017: 1118), which can influence subjectivity (Perz *et al.* 2014).

Reflecting the close perceived links between femininity and fertility, youthfulness and sexuality, EM/POI can also have complex impacts on gender identity (Parton *et al.* 2017, Singer 2012). Sex and intimacy for many women are inextricable from feeling physically attractive, and concerns about lacking 'reproductive potential' (Parton *et al.* 2017: 1114) or premature

ageing can contribute to feeling 'undesiring and undesirable' (Parton *et al.* 2016: 495). Embodied experiences, such as hot flushes and night sweats, can also precipitate a sense of 'estrangement' from one's body, compounded by perceptions of menopause as an 'older woman's' condition (Boughton 2002, Parton *et al.* 2017: 1118).

These biographical and subjective impacts of EM/POI have clear social dimensions, yet questions pertaining to women's personal relationships have not featured prominently in qualitative research. Nonetheless, this work suggests that heterosexual women's intimate relationships remain influenced by gender norms and age-related perceptions of menopause. EM/POI heralds an era of sexual freedom for some women (Pearce *et al.* 2014), however, more typically presents challenges to intimate relationships, especially in relation to sex and/or child-bearing (Karaöz *et al.* 2010, Parton *et al.* 2017, Singer 2012). Intimate relationships in turn influence women's experiences of and adjustment to EM/POI, though little is known about how (Abadi *et al.* 2018, Lockley 2012).

Family relationships have been examined even more sparingly, with indications that support from mothers and sisters can assist women's adjustment to EM/POI (Knobf 2008, Singer 2012). Some women describe greater affinity with older female relatives in sharing experiences of menopause, however, for others this exacerbates feelings of being 'out of synchrony' with peers (Parton *et al.* 2017: 50–2), a phenomenon Boughton termed 'social-self identity disruption' (2002: 428). In some families, menopause may be a taboo subject (Pasquali 1999), or family members may not know how to support women with EM/POI (Orshan *et al.* 2001). Friends and peers can be supportive (Knobf 2002), or, conversely, intensify feelings of disconnection, particularly in relation to partnering or having children (Orshan *et al.* 2001). Shame about EM/POI and complex emotions arising from an absence of shared experiences (Halliday *et al.* 2014, Knobf 2002) may compound this disconnect, contributing to feelings of isolation and a desire to meet others with EM/POI (Halliday and Boughton 2009).

Spontaneous and iatrogenic EM/POI have distinctive impacts for women and their relationships. Adjustment to spontaneous EM/POI can be challenging due to the often-unexpected nature of the diagnosis (Lockley 2012); lengthy diagnostic journeys (Boughton and Halliday 2008); and the absence of an identifiable cause in most cases (Orshan *et al.* 2001). Challenges unique to medically induced EM/POI include more severe symptoms (Gibson-Helm *et al.* 2014) and bodily transformations related to medical treatments (Solbrække and Bondevik 2015). Cancer-related EM/POI may entail further concerns about mortality, survival and/or fertility preservation (Brisbois 2014, Perz *et al.* 2014).

Few qualitative studies on the experience of EM/POI attend to the sociocultural changes arising from the intersections between gender, reproduction and technology (Latimer and Thomas 2017). We also know little of how women from diverse ethno-cultural or lower socioeconomic backgrounds, who identify as lesbian, bisexual or gender diverse or who live in the Global South experience EM/POI. Despite these limitations, as the review above makes clear, EM/POI can impact on women's biographies, subjectivities and relationships. However, the interlinkages between these dimensions have yet to be unpacked, limiting understanding of women's varied experiences of EM/POI. Below, we introduce some theoretical concepts for this task.

Conceptual framework

Part of the enduring appeal of the sociological concept of biographical disruption, pioneered by Bury in relation to the impact of chronic illness, is its acknowledgement that disruption occurs across several planes – biographical expectations, 'self-concept' and relationships – thereby linking individual experience with the social (1982: 169). Nonetheless, the concept has

been extensively refined and critiqued (see Locock and Ziebland 2015 for a review, Williams 2000). Of relevance to our article is its application to a wider range of health conditions and life course experiences, and recognition that not all illness experiences are perceived as disruptive (Locock and Ziebland 2015: 588). Indeed, EM/POI is neither a chronic illness, nor a necessarily disruptive experience (Knobf 2008).

In this article, we are interested in the connections between disruption to biographical expectations, subjectivity and personal relationships, and how these manifest and are renegotiated in narratives of EM/POI. Ketokivi's (2008) analysis of how relations with 'significant others' are 'reconfigured' following a life crisis is helpful here. Drawing on Bury (1982) and Frank (1995), Ketokivi argues that disruptive events 'wound' the self, through a rupturing of the 'taken-for-granted life and imagined future' and prompts it to become 'strange' to itself (2008: 258). The need for assistance mobilises the constitutive network of relationships the 'wounded self' exists within. However, Ketokivi asserts, responses vary depending by relationship type. Viewing the wounded self as a family member, not a 'suffering self', families tend to provide instrumental support (p. 266), while the need for emotional support drives the 'new' self to seek social recognition beyond the family. Further, the 'wounded self' is particularly drawn to others with similar experiences – 'fellows in fate' (Ketokivi 2008: 268) – in a quest for the healing and 'social legitimacy' needed to constitute the new self.

Although Ketokivi's insights into how relationships are implicated in biographical disruption resonate with our research and the literature, our work departs from hers in two main ways. Firstly, unlike Ketokivi, we include experiences (of EM/POI) that participants did not perceive as disruptive, thereby taking up Bury's injunction to examine how biographical disruption 'does or does not hold' (Locock and Ziebland 2015: 588). Secondly, unlike the experiences Ketokivi studied (e.g. divorce, depression), EM/POI is less common, and can dislocate women from not only an expected biographical trajectory, but also putative norms related to gender and age. Accordingly, achieving self and social recognition may be impeded by the difficulty of finding 'fellows in fate', ignorance of EM/POI and tenacious social expectations.

To better understand the significance of these potential impediments to self and social recognition of early menopausal subjectivities, we turn to Butler. Over several works (2015, 2007, 2005), Butler examines how norms, discourse, intersubjectivity and social recognition simultaneously structure and constrain one's ability to 'give an account of oneself', and recognise the other. Two points are particularly relevant. Firstly, Butler's invocation of Foucault's conceptualisation of subject formation (1985), which asserts that social norms structure and mediate both the kinds of subjects that can emerge and be recognised, and subjects' struggle to 'self-craft' in response to norms (Butler 2005: 19). Building on Ketokivi's insights into the search for recognition following biographical disruption, these ideas illuminate why the early menopausal self may struggle to be recognised. Although technology and social change have 'denaturalised' reproduction (Latimer and Thomas 2017: 811), it remains a domain of social life heavily influenced by gender norms. As Butler (2007: 191) explains, gender 'is an identity tenuously constituted in time'; the norms conditioning its emergence are also temporal. However, norms do not merely evolve or disappear without trace, but continue to influence ideas on who becomes recognised in social life alongside 'new' norms. Thus, if historically constituted gender norms valorising youth and fertility work to render menopausal women invisible (Ussher 2006), women with EM/POI are particularly unrecognisable within the (contested) social category of 'young woman'. Indeed, in 'breakdowns in the practice of recognition' such as those prompted by EM/POI, in order to be visible, the 'givenness of the prevailing normative horizon' must be called into question (Butler 2005: 24). Whether this is possible, however, is uncertain, which brings us to Butler's examination of specific, dyadic occasions of address, and the role of norms in shaping intersubjective interactions.

For Butler, our dependence on one another for mutual recognition is fundamental – 'we cannot exist without addressing and . . . being addressed by the other' (2005: 33) – but fraught with tension. While our respective 'singularity' paradoxically makes us the 'same', our individual differences separate us. Further, our uniqueness means that recognition is *always* contingent or may not be fully secured; the terms under which we are recognised are never fully of our own choosing. These differences lie *between* the norms that condition our emergence as a self, and how we negotiate those norms. This gap is unique to each self, elusive and cannot be narrated (Butler 2005: 38), making *any* account of oneself partial (p. 40).

In what follows, we draw on the insights of both Ketokivi on how relationships help 'wounded selves' secure recognition following a disruption, and Butler on the role of social norms in conditioning our continuous formation and mutual recognisability as subjects (2015: 6). These ideas facilitate understanding of women's experiences of forging 'new' early menopausal selves and illuminate why women with EM/POI experience differing degrees of biographical disruption.

Study and approach

Our findings are based on analysis of a subset of 25 transcripts from a qualitative study of experiences of EM/POI among 30 women living in Australia. Five transcripts were excluded from analysis – four from interviews with women whose menopausal symptoms resulted from adjuvant endocrine therapy or Turner Syndrome, different experiences from EM/POI in terms of biographical disruption, and one from a participant who chose not to discuss personal relationships in detail. The study was part of a National Health and Medical Research Council Partnership Project aimed at developing co-designed digital resources combining experiential and clinical information to support and inform women with EM/POI (healthtalkaustralia.org), in response to identified demand (Deeks *et al.* 2011). The authors were researchers (JF, KJA) and co-investigators (JB, MH, RK, HT, AV) on the study, which was guided by an interdisciplinary, cross-sectoral Reference Group including women with lived experience of EM/POI.

Women with diverse backgrounds and experiences participated (see Table 1). Interviewed between April 2017 and February 2018, women were recruited through specialist EM/POI clinics, cancer support/research organisations, universities, health promotion groups and professional clinical societies. Advertisements included a brief description of the study and researchers' contact details. Eligible women were invited to a narrative interview, audio or video-recorded according to their preference. Women gave informed, written consent, and were advised they could withdraw their participation at any time throughout the study.

During interviews, women were invited to narrate their experience of EM/POI in the context of their overall lives. Using a semi-structured interview format to ensure consistency of information collected, follow-up questions (where required) concerned early signs, experiences of diagnosis and treatment, symptoms, experiences with health practitioners, self-management of symptoms, daily life, work or study, personal relationships and thoughts about the future. Interviews lasted between one to three and a half hours, were conducted at a place and time chosen by participants and were transcribed verbatim. The Monash University and RMIT University Human Research Ethics Committees granted ethics approval (2016-1429; 2017-20985).

Participants

Participants' characteristics are presented in summary form in Table 1 below.

Table 1 *Participants' characteristics (N = 25)*

<i>Characteristic</i>	<i>N (unless otherwise stated)</i>
Age	
At interview	28–51 years
At diagnosis	25–44 years
Diagnosis	
Early menopause (EM)	10
Premature ovarian insufficiency (POI)	15
EM/POI type/cause	
Spontaneous EM/POI	10
Medically induced EM/POI	15
Following cancer treatment, including prophylactic bilateral salpingo-oophorectomy	11
Following treatment of benign conditions (adenomyosis, endometriosis, ovarian cysts)	4
Country of birth	
Australia	16
Overseas	9
Ethnocultural background (self-reported)	
Australian, British, Canadian, Irish	18
Chinese	1
Greek-Australian	1
Italian/Portuguese/German	1
Māori	1
‘Northern European’	1
Not stated	2
Relationships	
Single	8
Partnered	17
Sexuality	
Heterosexual	19
Bisexual	2
Lesbian	3
Not stated	1
Parenting	
≥1 child	12
Pregnant (self or partner)	2
No children	11
Educational level	
Post-secondary	23
Secondary	2
Paid employment	
Employed	21
Unemployed	4
Residence	
Metropolitan	17
Regional	8

Pseudonyms are used in this article and selected other identifying details have been altered to protect participants' anonymity.

Analysis

To illuminate the links between subjective impacts of EM/POI and women's personal relationships, we undertook a thematic narrative analysis of interview transcripts (Riessman 2008). Whereas thematic analysis typically entails identifying themes across multiple interview transcripts, thematic *narrative* analysis is 'case-centred' (Riessman 2008: 74). It involves keeping narratives 'intact' and a focus on their content rather than structure or audience (Riessman 2008: 53–4), as characteristic of other forms of narrative analysis. Data analysis began during data collection and while reading the literature on experiences of EM/POI, the impact of biographical disruption on self and personal relationships and theories of subject formation and 'recognition'. Over several readings of the transcripts, women's reflections on their shifting sense of self and personal relationships following EM/POI served as our 'unit of analysis' (Riessman 2008: 75), therefore we paid close attention to narrative content on these matters. After identifying narrative segments in which women discussed these topics, comparing these across interviews and in light of the empirical and theoretical literature, we identified three main narrative 'types'. These are narratives of interlude and continuity (self and relationships largely unaffected by EM/POI); of disruption and adaptation (integration of the new early menopausal self and adaptation of relationships); and of disruption and ambivalence (resistance to the early menopausal self and tension/unease within relationships).

Findings

Women's accounts suggested that most felt that they had 'changed' following the experience of EM/POI (Pam, medically induced EM at 41). Many also reported that their personal relationships had been implicated, both shaping their adjustment to and being impacted by EM/POI. However, a few women portrayed the experience as not especially disruptive and their relationships as largely undisturbed. Perceptions of the extent to which EM/POI had disrupted women's lives or sense of self were influenced by several, interlinked aspects of their experiences. These included women's 'location' in their imagined biographies, whether they experienced embodied changes associated with menopause as bothersome, and cause of EM/POI. The extent to which women identified with norms related to gender and age was also significant, as was the importance their partners, families and friends attached to these. Below we discuss three narrative 'types' characteristic of how EM/POI interlinked with our participants' self-identity and personal relationships. Each section begins with a description of the women in the group, followed by analysis of an exemplar narrative, further illustrated by excerpts from other interviews.

Interlude and continuity

Five women interviewed neither portrayed EM/POI as a biographical disruption, nor conveyed a sense that their relationships or sense of self had changed significantly. One had spontaneous POI, and four had medically induced EM (all cancer-related), all of whom emphasised cancer as significantly more disruptive than EM, which they considered a necessary consequence of survival. Compared with the two subsequent groups, women with narratives of 'interlude and continuity' were older at diagnosis (39–43 years), expressed contentment with their family circumstances, experienced symptoms that were either mild or well-managed by MHT, did not hold particularly 'traditional' gender norms related to motherhood, nor expressed concern

about the impact of EM/POI on their physical appearance. Four women were partnered, three had children and all described positive and supportive relationships with partners, family members and friends. Aisling's narrative illustrates several themes found across all five interviews.

Aged 47 and of British background, Aisling worked full-time in a professional role and was in a heterosexual relationship with two children. After being diagnosed with spontaneous POI at age 39, she recalled experiencing intermittent hot flushes for 'a couple of years' but no other symptoms, concluding that she 'had it quite easy'. Aisling was reportedly neither offered nor wanted MHT, asserting that menopause was 'an entirely normal process'.

The impact of POI on Aisling's subjectivity did not seem particularly disruptive – she mentioned feeling only 'a bit of a sense of not being quite whole as a woman' on realising she could not have more children:

I've never been particularly feminine. I never thought that my purpose in life was to have children but to have that choice removed is still, briefly, a moment of (. . .) I don't want to say loss or sadness. Poignancy? There is a moment of reflection. (. . .) [pause] Probably it was made easier because I've never been geared up just to have children. (. . .) I felt that I'd done that part of my life. In fact I think my partner had the snip by then anyway. [laughter] So maybe that meant that that reflective moment was reduced in its intensity. (. . .) I don't think [my partner and I] even talked about it a lot.

Aisling's personal circumstances and her self-identification as not 'geared up just to have children' and therefore not 'particularly feminine', seem to have blunted the effects of EM/POI on her subjectivity. We further suggest that the two subject positions Aisling adopted in her narrative (mother and woman for whom childbearing is *not* a central aspect of identity) were recognisable within the 'normative horizon' characteristic of her highly educated, middle-class Anglo-Australian milieu (Butler 2005: 24). Nonetheless, given that 'mother' generally remains the more culturally valorised of the two subject positions (Dryden *et al.* 2014: 1342), this status was, we argue, key to Aisling's relatively smooth transition to a menopausal self. However, the experience of Holly (medically induced EM at 41) underlines how a feminine identity not strongly influenced by dominant social norms regarding youth and fertility could facilitate adaptation to an early menopausal subjectivity. As she reflected, 'I have it easier than a lot of people, because of the timing [of EM] – I had no interest in having children. That time had passed'.

Also facilitating Aisling's adjustment to POI were the impacts on, and of, her personal relationships. Describing herself and her husband as similarly 'pragmatic', she explains:

. . . we're just not the sort of people to sit and reflect and have deep and meaningful about, "Oh, how do you feel about menopause, dear?" (. . .) I think the biggest impact on our relationship was having two [children] under two (. . .) I didn't get depressed about [POI] and I didn't have that many terrible symptoms (. . .) I just got on with being a mother to the kids that I had (. . .) and in some ways, after maybe a year or so, it probably had a positive impact on the relationship because we were just able to enjoy life or not worry about whether we might run the risk of having another baby.

Aisling suggests POI had few negative implications for her marriage, partly due to her husband's lack of concern about it, and because early parenthood by comparison had put more strain on their relationship (Kokanović *et al.* 2018). Elsewhere in her interview, she also describes being unconcerned by her friends' reported lack of interest in her experience of POI; the main relationship Aisling discussed in relation to POI was with her daughter, given her concern the condition might be genetic.

POI, then, was an interlude in Aisling's biography, subjectivity and personal relationships, which were otherwise largely undisturbed. She, and the other women in this group, described needing little instrumental or emotional support for EM/POI (though some needed support in relation to cancer). Either their identities had been little impacted, or they had accepted the changes wrought by EM/POI by positioning cancer and/or recurrence as relatively more distressing. Pam (medically induced EM at 41), for example, described EM as 'nothing compared to breast cancer treatment'. As Butler (2005: 35) argues, 'recognisability' is established and maintained in relation to social norms. Women with narratives of 'interlude and continuity' expressed little attachment to gendered norms that often constitute youthful female subjectivity such as fertility and sexual desirability (Parton *et al.* 2017). Nonetheless, the elasticity of those norms is such that experiences of EM/POI remain (however loosely) structured around them, as seen in both Aisling's and Holly's remarks.

Disruption and adaptation

For eight women, the experience of EM/POI was characterised by disruption and adaptation. However, their narratives suggested they had come to accept their early menopausal selves, and their relationships had evolved. Four women had spontaneous EM/POI, four had medically induced EM/POI (two cancer-related), and age at diagnosis was 25–44 years. Seven women described their family arrangements as different from what they had hoped for, which they attributed to the impact of EM/POI. All had reportedly wanted children, but seven had either none or fewer than desired, while two of the four single women still hoped to find a partner. Menopausal symptoms had been challenging for all but one woman. Five were taking MHT and reported it had alleviated their symptoms. In general, women described good communication with and acceptance from partners, family members and/or friends in relation to EM/POI.

Key aspects of 'disruption and adaptation' are captured in the narrative of Kerry, a 48-year old heterosexual woman with English heritage, married with one child, who worked in a full-time professional role. Kerry experienced iatrogenic EM at 44 following a hysterectomy for endometriosis. Her gynaecologist reportedly did not explain that the surgery might cause EM, and Kerry was not diagnosed with the condition until two months after her hysterectomy. Because of a family history of breast cancer, her doctor advised her against taking MHT³. Aided by lifestyle and dietary changes Kerry described eventually learning to 'live with' hot flushes, emotional volatility, insomnia, aching joints, and fatigue.

Reflecting on the subjective impacts of EM, Kerry observes:

. . . it is a huge lifestyle change. It's as dramatic for me going through menopause as it is for a teenager, because I went from hormones to no hormones [laughter] (. . .) So when I'm trying to describe it to my child, [I say] I was going through 'un-teenagerhood' (. . .) it's a huge knocked confidence. Because you change; you physically have changed. You emotionally change. You psychologically change.

In her narrative, Kerry emphasised that the disruption she experienced following EM stemmed from a lack of information and forewarning, being unable to take MHT and significant embodied changes. Despite feeling she had changed 'physically', 'emotionally' and 'psychologically', Kerry's account was distinctive among the eight narratives of 'disruption and adaptation' in that she did not attribute these changes to loss of fertility, 'youth' or perceived sexual attractiveness but to loss of hormones. By comparison, Lucia (spontaneous POI at 25) associated a change in her sense of self with not only hormonal and physiological impacts, but also the confrontation she felt POI had occasioned with social expectations that 'women are made to

be mums' and family pressure to partner and have children. This reflects Butler's (2005: 38) arguments on the normative 'conditions of [one's] emergence' and the 'exposure to the other'. The 'new' early menopausal self cannot emerge in isolation from others, whether proximate (as in Lucia's experience) or more distant. Suzanne (spontaneous EM at 42), for example, wondered whether people could tell that she had undergone menopause 'just by looking' at her. However, the response of 'others', the nature of their relationship to the self and their attachment to social norms also shape that process of emergence, as we discuss below.

In Kerry's view, her 'whole family' had been affected by her experience of surgical menopause, and, as indicated by her remarks above about her child, she sought recognition of her changing self within this setting. The dynamics of the interplay between Kerry's thoughts and feelings about her early menopausal self, her efforts to articulate these to her family and their reactions are further elaborated in the following extract:

. . . it's hard to be sexy when you're cranky [laughter].(. . .) to think of yourself as a sexual being when you are experiencing hot flushes every hour and you're going, 'I don't want anyone near me. All I want to do is feel cool. (. . .) you've got to open a whole new conversation up with the loved ones in your lives about this, that things have changed. You're not the person you were before surgery or menopause. (. . .) [intimacy] changes. Things become a little bit longer, you've got to just warm up to the idea and also [laughter], 'Okay, I've got to think about this. Do I really want to have intimacy as part of my life? Yes I do. And what can I do to sort of get around it?' And then also have a sense of humour about, 'My gosh, I'm going to have a hot flush, it's not very sexy'. And just working that out and having someone who goes, "It's all right, you're experiencing a hot flush. It's part of life,"

Although Kerry's identity as a 'sexual being' was challenged, acceptance from herself and her husband that 'things' had 'changed' enabled their relationship to adapt, and Kerry to bring her altered self into intimate encounters. These, and similar comments she made about other family members, suggest that they were able to 'see' Kerry's new self, their acknowledgement, acceptance and affection working to provide social recognition. In contrast to Ketokivi's conceptualisation of how relationships are reconfigured following a biographical disruption, Kerry's family was indeed trying to 'grasp the disruptive experience' (2008: 266), rather than treat her as a 'wounded' member of the family by focussing on material support.

Kerry also actively sought emotional support and recognition outside the family, by deliberately being open about EM, and seeking 'fellows in fate'. Disclosing EM helped her solicit information about menopause from older friends and raise awareness of EM/POI among younger friends. In so doing she was 'calling into question' prevailing norms of youthful femininity (Butler 2005: 24). Other women with narratives of 'disruption and adaptation' achieved this by responding to 'intrusive' or 'upsetting' questions about having children by disclosing their experience of EM/POI, to both 'break some stereotypes' (Zoe, spontaneous POI at 31) and make clear that such questions were deeply personal. However, although talking about EM/POI helped women acknowledge their evolving subjectivities, it did not always provide social recognition. Carmel (spontaneous EM at 40) recalled when telling her friends about EM, '[t]hey were as supportive as they could be. But (. . .) I don't think anyone really got it'. Consequently, many women described searching for support groups or others with similar experiences. Having failed to find a support group, Kerry appreciated the 'understanding' she felt sharing her experiences with two new acquaintances who had undergone hysterectomies. Connecting with such 'fellows in fate' was critical to Kerry's search for self and social recognition, as it was for other women whose accounts are grouped here.

While EM was significantly disruptive for Kerry and other women with narratives of 'disruption and adaptation', they described strong, supportive networks of friends, family or fellow 'sufferers', and a propensity to question gender norms linking femininity with reproduction and youthfulness. These aspects of women's experiences seemed to make the 'break' with constitutive norms and search for countervailing norms easier, in turn facilitating the process of forging and gaining recognition for a new early menopausal self, and the reshaping of relationships. Often, narratives followed a 'quest' or 'redemptive' arc (Frank 1995), as encapsulated in Kerry's characterisation of herself following EM/POI as a 'cocoon transforming into a butterfly'.

Disruption and ambivalence

The accounts of the 12 women we describe as narratives of 'disruption and ambivalence' were suffused with profound emotional distress, frustration, ambivalence or resignation. Their perceptions of the impacts of EM/POI seemed associated with feeling more unsettled personally and within key relationships. Seven women experienced iatrogenic EM/POI (six cancer-related) and five had spontaneous EM/POI; age at diagnosis was 30–44. Four women were comfortable with their family arrangements, while eight had no or fewer children than hoped for, and/or were single and wanted a partner. Two women were taking MHT; ten were unable to due to side-effects or cancer type and most found their symptoms challenging. Compared with accounts discussed earlier, women whose interviews are analysed in this section attached greater importance to the impacts of EM/POI on fertility, perceived 'attractiveness' and sexuality. All described significant relationships in which their early menopausal self was not fully 'recognised' or emotional support was unavailable. Harriet's account is illustrative of the narratives grouped here.

Aged 41 at her interview, Harriet was diagnosed with POI at 37 following chemotherapy for Stage 4 Hodgkin's Lymphoma. She was of Anglo-Celtic background, worked full-time in a professional role and lived with her same-sex partner, Thea, and baby (conceived via IVF using Thea's egg and donor sperm, and carried by Thea). POI was one of several biographical disruptions that Harriet had experienced within a few years – her mother's illness and death from cancer, the breakdown of Harriet's previous relationship (in which children had been planned, with Harriet as the carrying mother) and her cancer diagnosis. Accepting POI and her altered biographical trajectory had been challenging:

I had started a new relationship and Thea was very upfront from the outset about wanting children and (. . .) I'd sort of thought, you know, 'I was going to be the one to have children back in the old life, old relationship, everything', . . . that was a bit of an adjustment I guess. At the time I was still struggling with body image and (. . .) regain[ing] my pre-cancer body and sense of self and (. . .) you're having conversations about hot sweats with the well-meaning 55-year old women in your office but you're thinking (. . .) 'This is ridiculous'. (. . .) 'All of this shouldn't be happening to me at this age'.

Harriet's frustration at the unexpected turn her biography had taken, sense of dislocation from her peers, and attachment to perceived gender and age-related norms meant that she could only 'see' her post-POI, post-cancer self in terms of loss. The above and other extracts suggest Harriet had become an object to herself (Ketokivi 2008: 275), preoccupied with how she was seen by others; as both different from her previous self, and not living up to gendered norms of youth, fertility and sexuality.

Experiencing POI in the context of a new intimate partnership and a family network disrupted by her mother's death made recognising her changed self additionally challenging for

Harriet. Her uncertainty over why her ‘body wasn’t responding’ to Thea and feelings of having changed translated into difficulties accounting for ‘who’ she was to her new partner. As she explained, intimacy ‘is hard to talk about and when someone hasn’t known you prior to cancer, it’s like you were a different person then, and it’s hard to explain that’. Harriet’s experience evokes Butler’s (2005) observations about the contingencies inherent in any account of oneself, related to time, the body and the ‘scene of address’ (here, to a new partner). In ‘failing’ to behave in expected ways following POI, Harriet’s body had precipitated a ‘break’ with norms that had shaped her previous self. At such times of ‘significant rupture’, Butler suggests that ‘we may not know precisely who we are’ (2015: 9), or who we might become. The embodied effects of POI had thus disrupted Harriet’s ability to articulate a ‘self’ that both she and Thea could recognise. An already complex task when the ‘other’ is known (as illustrated in Kerry’s account), it is more intensely so when the ‘other’ is a new acquaintance, an experience narrated by several other women who experienced EM/POI while dating or in new relationships.

In her mother’s absence, Harriet could also only talk with certain family members about what POI meant for her:

. . . from a family perspective, if you were going to talk to anyone you’d talk to your mum about it (. . .) I felt like my dad and my brother didn’t acknowledge how big an impact it would have on me to know that I couldn’t have children, and I just sort of thought ‘You should get this’, (. . .) in terms of support, I guess the two family members who were closest to my mum would be my aunt and my mum’s cousin who I would be able to speak to [about POI]. (. . .) So that’s been important.

This extract illustrates that, in contrast to the experiences of Kerry and other women discussed above, family relationships could not always be re-shaped to offer the emotional support desired to facilitate self and social recognition of new early menopausal selves. Consistent with Ketokivi’s framework (2008), Harriet’s father and brother could ‘only’ provide instrumental support (e.g. paying for her fertility preservation medication). For emotional support, she sought out older female relatives, but found this frustrating because of differing life stages.

Elsewhere in her account, Harriet described wanting to talk about POI with someone with ‘more commonalities’ but had not found such a person. Likewise, Vanessa (spontaneous POI at 37), for instance, only experienced ‘validation’ of her experience as an involuntarily childless woman through an online community. Some knew other women who had experienced EM/POI or infertility but struggled to overlook differences in their circumstances. Anastasia (spontaneous POI at 30) said of an acquaintance who experienced EM: ‘part of me thinks, “But you’ve got kids, how can you be so upset about having EM?”’. This perspective reflects the distancing aspect of our ‘singularity’ or uniqueness that limits ‘the model of reciprocal recognition . . . and the possibility of knowing one another’ (Butler 2005: 31). Being unable to find, or bridge differences with, ‘fellows in fate’, most women discussed here described seeking recognition in existing relationships, and feelings of disappointment or frustration when emotional support or recognition was not offered. This was particularly acute for women for whom POI had initiated a ‘severe disorientation’ (Butler 2015: 9) from their previous selves. Yet to encounter countervailing norms that might replace those norms that previously crafted their self-identity, for these women a lack of peers with similar experiences seemed to make this possibility less likely and entrench their isolation.

Harriet’s ambivalence about her post-POI self and the tensions in her relationships were echoed in the other narratives analysed here. Women were less likely to express a sense of having found meaning in their experiences, with several comparing their circumstances with

what they 'should' have been experiencing if not for EM/POI. This apparent resistance to their changed reality translated into ambivalence about their early menopausal selves, and dissatisfaction in particular relationships. Adjustment to EM/POI and the formation of an early menopausal subjectivity was further impeded by family members' or friends' failure to 'grasp the disruption' (Ketokivi 2008: 256) or continued attachment to gendered norms, and women's inability to find 'fellows in fate' in whom to confide.

Conclusion

A recurrent finding in the qualitative literature on experiences of EM/POI is that the condition commonly precipitates biographical disruption, rupturing the intertwined 'planes' of biographical expectations, sense of self and relationships (Bury 1982). However, the impacts of EM/POI on personal relationships have received comparatively little attention; the links with impacts on biography and subjectivity even less. These gaps in knowledge matter. Understanding how to better support women experiencing EM/POI is important, particularly as the number of women with the condition grows, reflecting rising rates of cancer survivorship. More tailored care also aligns with health practitioners' increasing acknowledgement that individuals' personal relationships influence their health and wellbeing, as part of patient-centred care (Institute of Medicine 2001).

To redress these omissions, our article explored the complex enmeshments of personal relationships in the formation of early menopausal selves, articulated in 25 narratives of experiences of spontaneous and medically induced EM/POI. Informed by a conceptual framework drawing on the notion of biographical disruption (Bury 1982, Williams 2000), Ketokivi's insights into the reconfiguration of personal relationships following disruption (2008), and Butler's theorising about the role of social norms in relation to subject formation and social recognition (2005, 2007, 2015), we identified three narrative types characterising how women's sense of self and relationships shaped and were shaped by their experience of EM/POI. These included narratives of interlude and continuity; of disruption and adaptation; and of disruption and ambivalence.

Often a significant embodied experience that displaces 'sufferers' from a putative normative young, female biography, EM/POI offers a rich landscape for exploring the intersection of biology, social norms, subjectivity and relationality. Women's accounts reveal how, in crafting new early menopausal subjectivities, they must confront and renegotiate their relationship with powerful but ever-evolving 'normative horizons' (Butler 2005: 24) that define the range of youthful femininities recognisable to self and other. By foregrounding relationships and tracing how these ties were implicated in women's experiences of adjusting to EM/POI, our article extends understanding of the reasons women vary in the degree of biographical disruption they associate with the condition. We found that, across the three narrative types, identification with gendered norms related to reproduction and age, on the part of women and those around them, mediated the influence of other factors identified in previous work (see Knobf 2008). While many women recounted grappling with 'old' norms, 'interlude and continuity' narratives suggest that emerging norms of femininity less tightly tied to reproduction are becoming salient.

As noted earlier, the qualitative literature on EM/POI to date has engaged little with the broader sociocultural context of shifting patterns and norms of personal and family life and increasingly diverse populations. Our study also reflects this limitation to a certain extent. Despite efforts to recruit a demographically diverse sample, well-educated and/or culturally 'Anglo-Celtic' women predominated. Greater participation by women from other backgrounds may yield different findings and we encourage other researchers to take up this task. Careful

attention to women's experiences and perspectives is necessary to determine the extent of disruption and the need for support. In a clinical context, such support may include health practitioners working with women and their family members to unpack normative values and beliefs and their potential influence on the experience of EM/POI.

Finally, our findings also add to ongoing work on biographical disruption and interlinkages between biographical, subjective and relational impacts, particularly Ketokivi's theorisation of the role of personal relationships in supporting 'wounded selves' following disruption (2008). Ketokivi focuses on how the configuration of different ties within a network of relationships shifts, with each type of relationship portrayed as providing static forms of support. In contrast, we found that individual relationships often evolved to provide the kind of support women wanted. This potential for change was closely connected to individuals' capacity for reflexivity in relation to gender and age-related norms – a capacity which, as we suggest above, personalised care that accounts for women's relationships may be able to strengthen. On the other hand, many women's expressed wish to meet others with similar experiences affirms Ketokivi's insights into the importance of 'fellows in fate' in securing recognition of one's changed sense of self following disruption. Given women with EM/POI rarely encounter one another, this finding underlines the dual importance of expanding awareness of the condition and formal support resources that capture diverse experiences.

Address for correspondence: Kate Johnston-Ataata, Social and Global Studies Centre, RMIT University, Melbourne, VIC 3000, Australia. E-mail: kate.johnston-ataata@rmit.edu.au

Acknowledgements

The authors would like to acknowledge project partners and funders National Health and Medical Research Council (APP1116008), National Breast Cancer Foundation, Australasian Menopause Society, Breast Cancer Network Australia, Endocrine Society of Australia, Healthdirect Australia, Healthtalk Australia, Monash Health, and Women's Health Victoria, members of the Reference Group and the women who participated in the study. This research was also supported by Register4 through its members' participation. The authors thank the editors and reviewers for their helpful feedback.

Notes

- 1 Within this article, a biomedical understanding of EM/POI is our departure point. We acknowledge that other discourses exist, including feminist perspectives (see Ussher 2006), but employ a biomedical framing because our participants drew primarily on this discourse.
- 2 With the exception of women with hormone sensitive cancer.
- 3 This is not necessarily a reason to avoid MHT (Collaborative Group on Hormonal Factors in Breast Cancer 2019).

Data availability

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

References

- Abadi, O., Cheraghi, M., Tirkari, B., Nayeri, N., *et al.* (2018) 'Feeling an invisible wall', the experience of Iranian women's marital relationship after surgical menopause: a qualitative content analysis study, *Journal of Sex & Marital Therapy*, 44, 7, 627–40.
- Anderson, D., Yates, P., McCarthy, A., Lang, C.P., *et al.* (2011) Younger and older women's concerns about menopause after breast cancer, *European Journal of Cancer Care*, 20, 785–94.
- Becker, G. (1997) *Disrupted Lives: How People Create Meaning in a Chaotic World*. Berkeley: University of California Press.
- Brisbois, M. (2014) An interpretive description of chemotherapy-induced premature menopause among Latinas with breast cancer, *Oncology Nursing Forum*, 41, 5, E282–89.
- Boughton, M. and Halliday, L. (2008) A challenge to the menopause stereotype: young Australian women's reflections of 'being diagnosed' as menopausal, *Health & Social Care in the Community*, 16, 6, 565–72.
- Boughton, M. (2002) Premature menopause: multiple disruptions between the woman's biological body experience and her lived body, *Journal of Advanced Nursing*, 37, 5, 423–30.
- Bury, M. (1982) Chronic illness as biographical disruption, *Sociology of Health & Illness*, 4, 2, 167–82.
- Butler, J. (2015) *Senses of the Subject*. New York: Fordham University Press.
- Butler, J. (2007) *Gender Trouble: Feminism and the Subversion of Identity*. New York and London: Routledge.
- Butler, J. (2005) *Giving an Account of Oneself*. New York: Fordham University Press.
- Collaborative Group on Hormonal Factors in Breast Cancer (2019) Type and timing of menopausal hormone therapy and breast cancer risk: Individual participant meta-analysis of the worldwide epidemiological evidence, *Lancet*, 394, 1159–68.
- Deeks, A., Gibson-Helm, M., Teede, H. and Vincent, A. (2011) Premature menopause: a comprehensive understanding of psychosocial aspects, *Climacteric*, 14, 565–72.
- Dryden, A., Usher, J. and Perz, J. (2014) Young women's construction of their post-cancer fertility, *Psychology & Health*, 29, 11, 1341–60.
- ESHRE (2016) *Information for Women with Premature Ovarian Insufficiency*. Grimbergen: European Society of Human Reproduction and Embryology. Available at <https://www.eshre.eu/Guidelines-and-Legal/Guidelines/Management-of-premature-ovarian-insufficiency> (Last accessed 13 May 2019).
- Foucault, M. (1985) *The History of Sexuality, Vol. 2: The Use of Pleasure*. New York: Random House.
- Frank, A. (1995) *The Wounded Storyteller: Body, Illness and Ethics*, 2nd edn. Chicago: University of Chicago Press.
- Gibson-Helm, M., Vincent, A. and Teede, H. (2014) Symptoms, health behaviour and understanding of menopause therapy in women with premature menopause, *Climacteric*, 17, 666–73.
- Halliday, L. and Boughton, M. (2009) Premature menopause: exploring the experience through online communication, *Nursing & Health Sciences*, 11, 1, 17–22.
- Halliday, L., Boughton, M. and Kerridge, I. (2014) Mothering and self-othering: the impact of uncertain reproductive capacity in young women after haematological malignancy, *Health Care for Women International*, 35, 249–65.
- Hampshire, K., Blell, M. and Simpson, B. (2012) 'Everybody is moving on': infertility, relationality and the aesthetics of family among British-Pakistani Muslims, *Social Science & Medicine*, 74, 1045–52.
- Hollway, W. (2006) Paradox in the pursuit of a critical theorisation of the development of self in family relationships, *Theory & Psychology*, 16, 4, 465–82.
- Institute of Medicine (2001) *Crossing the Chasm: A New Health System for the 21st Century*. Washington: The National Academies Press.
- Karaöz, B., Aksu, H. and Küçük, M. (2010) A qualitative study of the information needs of premenopausal women with breast cancer in terms of contraception, sexuality, early menopause, and fertility, *International Journal of Gynecology & Obstetrics*, 109, 2, 118–20.
- Ketokivi, K. (2008) Biographical disruption, the wounded self, and the reconfiguration of significant others. In Widmer, E. and Jallinoja, R. (eds) *Beyond the Nuclear Family: Families in a Configurational Perspective*. Bern: Peter Lang AG, pp. 255–77.

- Kokanović, R., Michaels, P.A. and Johnston-Ataata, K. (eds) (2018) *Paths to Parenthood: Emotions on the Journey Through Pregnancy, Childbirth, and Early Parenting*. Singapore: Palgrave Macmillan.
- Kokanović, R. and Flore, J. (2017) Subjectivity and illness narratives, *Subjectivity*, 10, 4, 329–39.
- Knobf, T. (2008) ‘Coming to grips’ with chemotherapy-induced premature menopause, *Health Care for Women International*, 29, 4, 384–99.
- Knobf, T. (2002) ‘Carrying on’: the experience of premature menopause in women with early stage breast cancer, *Nursing Research*, 51, 1, 9–17.
- Latimer, J. and Thomas, G. (2017) The politics of reproduction and parenting cultures – procreation, pregnancy, childbirth and childrearing, *Sociology of Health & Illness*, 39, 6, 811–5.
- Lockley, G. (2012) Premature menopause: the experiences of women and their partners. Doctor of Psychology thesis, Swinburne University of Technology, Melbourne.
- Locock, L. and Ziebland, S. (2015) Mike Bury: Biographical disruption and long-term and other health conditions. In Collyer, F. (ed.) *The Palgrave Handbook of Social Theory in Health, Illness and Medicine*. Houndsmill Basingstoke: Palgrave Macmillan, pp. 582–98.
- Orshan, S., Furniss, K., Forst, C. and Santoro, N. (2001) The lived experience of premature ovarian failure, *Journal of Obstetric, Gynaecological and Neonatal Nursing*, 30, 2, 202–8.
- Parton, C., Ussher, J. and Perz, J. (2017) Experiences of menopause in the context of cancer: women’s constructions of gendered subjectivities, *Psychology & Health*, 32, 9, 1109–26.
- Parton, C., Ussher, J. and Perz, J. (2016) Women’s construction of embodiment and the abject sexual body after cancer, *Qualitative Health Research*, 26, 4, 490–503.
- Pasquali, E. (1999) The impact of premature menopause on women’s experience of self, *Journal of Holistic Nursing*, 17, 4, 346–64.
- Pearce, G., Thøgersen-Ntoumani, C., Duda, J. and McKenna, J. (2014) Changing bodies: experiences of women who have undergone a surgically induced menopause, *Qualitative Health Research*, 24, 6, 738–48.
- Perz, J., Ussher, J. and Gilbert, E. (2014) Loss, uncertainty or acceptance: subjective experience of changes to fertility after breast cancer, *European Journal of Cancer Care*, 23, 514–22.
- Riessman, C. (2008) *Narrative Methods for the Human Sciences*. Thousand Oaks: Sage.
- Shuster, L., Rhodes, D., Gostout, B., Grossardt, B., *et al.* (2010) Premature menopause or early menopause: long-term health consequences, *Maturitas*, 65, 2, 161–6.
- Singer, D. (2012) ‘It’s not supposed to be this way’: psychological aspects of a premature menopause, *Counselling and Psychotherapy Research*, 12, 100–8.
- Solbrække, K. and Bondevik, H. (2015) Absent organs – present selves: exploring embodiment and gender identity in young Norwegian women’s accounts of hysterectomy, *International Journal of Qualitative Studies on Health and Wellbeing*, 10, 26720, <https://doi.org/10.3402/qhw.v10.26720>.
- Williams, S. (2000) Chronic illness as biographical disruption or biographical disruption as chronic illness?, Reflections on a Core Concept, *Sociology of Health & Illness*, 22, 1, 40–67.
- Ussher, J. (2006) ‘The horror of this living decay’: Menopause and the ageing body. In Ussher, J. (ed.) *Managing the Monstrous Feminine: Regulating the Reproductive Body*. East Sussex: Routledge, pp. 118–50.