Couldn't care less?

A psychosocial analysis of contemporary cancer care policy as a case of borderline welfare

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This article engages with recent shifts in public healthcare policy in Norway through a psychosocial analysis of contemporary cancer care, which evokes the hope of cure and reparation in the psychosocial imaginary. With increasing incidence and prevalence, cancer is a persistent challenge for public health services. Policy makers therefore emphasise that resources must be prioritised while ensuring good-quality care for vulnerable citizens. In 2015, Norway implemented integrated patient pathways as national guidelines to standardise clinical assessment and medical treatment for patients with a suspected cancer diagnosis. In a text analysis of ‘the integrated breast cancer pathway’ as a framework for practice, we found the concept and practice of care absent. There were sparse descriptions of the relational responsibilities of health professionals, beyond informing and communicating. From a psychosocial care understanding, we problematise how the emphasis on information delivery presupposes a universally autonomous, competent, resilient and rational patient, rather than a particular human being with complex thoughts, feelings, needs and vulnerabilities in the face of a life-threatening illness. We refer to wider issues effected by neoliberal governance, which may profoundly impact on the relationship between professionals and patients. We raise the concern that integrated cancer care is a case of borderline welfare, characterised by a fear of feelings associated with mutual vulnerabilities and dependencies. We identify values and ethical pressures at stake in an emerging careless policy in Norwegian welfare, in light of the government’s stated ambition to become an international role model for good patient trajectories.

**Key words** psychosocial care • cancer care • healthcare policy • psychosocial imaginary • ethical pressure
Introduction

In this article, we engage with recent shifts in public healthcare policy in Norway through a psychosocial analysis of contemporary cancer care. One such policy shift concerns demands for the prioritisation of resources and increased quality in services, agendas that appear to be irreconcilable. A breast cancer treatment guideline provides our grounds for exploring quality in cancer care as an area of practice in the specialist health services that has undergone a policy-driven transformation in the form of ‘integrated patient pathways’.

Beyond ‘the reality’ of the clinic in which the effort is to save or prolong lives, cancer policy could be said to respond to and feed into a psychosocial imaginary pertaining to ideals and reassurances of cure and reparation (see, for example, Fotaki, 2006). In such an imaginary, desires and fantasies of ‘doing good’ relate to a disease that is perceived socioculturally as ‘the emperor of all maladies’ (Mukherjee, 2010) – evoking a ‘nameless dread’ (Bion, 1962). In this sense, cancer policy can also be studied as the articulation of a psychosocial defence against suffering, fear of annihilation or mutilation, which may provide emotional containment for the uncertain or unbearable.

In what follows, we show how policy makers at the macro level construct a framework for the institutions’ and healthcare professionals’ meso- and micro-level production of cancer treatment, which may be detrimental to a containing function. We discuss how this framework may challenge quality of care by introducing a psychosocial understanding of care, sensitive to the intersubjective affects and vulnerabilities that characterise all human relations, not least those in the practice field of cancer care.

Background

The emergence of neoliberal healthcare policy in Norway

Since the late 1980s, public welfare in Scandinavia has undergone changes – with some variations nationally – broadly related to the development of a more competitive state. This ‘competition state’ (Pedersen, 2011) is one manifestation of the global ‘compulsory agenda of neoliberalism’ (Vetlesen, 2011) to secure competitive ability at all levels of society. Correspondingly, Norwegian healthcare has been the target of reforms associated with New Public Management (NPM), which were implemented to increase productivity and curtail costs (Veggeland, 2013). Despite the national consensus that healthcare should be public and financed by the state, Norway has increased privatisation of services and freedom of choice for ‘users’, in line with marketisation. Related to this is the emergence of a ‘patient-centred approach’ in the late 1990s (Veggeland, 2013), but nearly two decades later, White Paper 11 reports that patients perceive health services as ‘good when it comes to survival but not so good
when it comes to experience’ (Norwegian Ministry of Health and Care Services, 2015: 9). Specialist health services have been strongly affected by NPM since the Health Trust Reform of 2002, which shifted hospital ownership into a semi-state enterprise (Pettersen, 2017). This was accompanied by a performance-based system for financing, supported by corporate management principles based on a ‘rational action–oriented logic’ (or ‘managerialism’), where performance outcomes are central (Steenberg et al, 2018: 57). Whereas Denmark and Sweden have called for a ‘trust reform’ in response to NPM welfare, Norway appears committed to a neoliberal governance agenda, despite professional unrest as evidenced by the emergence of a new anti-NPM activist group (‘Helsetjenesteaksjonen’) in 2013 and a record-long hospital doctors’ strike in 2016.

Values in the Patient’s Health Service

In 2014, the launch of White Paper 34, Values in the Patient’s Health Service (Norwegian Ministry of Health and Care, 2015–2016) signalled a new era in healthcare, epitomised by the slogan ‘the patient’s health service’. Priorities in welfare provision are a shared concern in the Nordic context, which has ‘paved the way for neo-liberal political projects and organisational management principles’ (Andersen and Dybbroe, 2011: 262). Norway upholds the idea that in order to sustain a good, just and equal public healthcare system, the prioritisation of resources and treatment is necessary in order to ‘help those who need it the most first’ (Norwegian Ministry of Health and Care, 2015–2016: preface). However, welfare state prioritisation is not solely an issue of economic cost, but should also be based on shared values, dignity, equality and justice, central to the constitution. A citizen’s right to the highest possible standard of healthcare is an undisputed ideal. Accordingly, White Paper 34 states that the ‘healthcare service shall be there for us when we are at our most vulnerable’, but also provides principles to help healthcare personnel ‘cover their backs in decisions they take in their encounters with patients’ (Norwegian Ministry of Health and Care, 2015–2016: preface).

Integrated cancer pathways in the patient’s health service

Cancer is a considerable societal challenge, as its incidence and prevalence are increasing. In developed countries, the future lifetime risk of developing cancer is projected to be one in two (Ahmad et al, 2015). For many, cancer will become a chronic condition, requiring sustained medical supervision over years. With biomedicine advancing increasingly complex and personalised treatment strategies, specialist health services will be correspondingly stretched in terms of financial and human resources. Cancer care has been the object of sustained policy attention in Norway. Within fewer than five years, two cancer reforms were implemented, with the aim of diagnosing, treating and discharging cancer patients more effectively (Norwegian Ministry of Health and Care Services, 2011; Norwegian Directorate of Health, 2016b). Both reforms were based on the premise that patients benefit from, and are reassured by, standardised treatments that follow predictable trajectories, ensuring information delivery and user involvement. Integrated pathways, imported from Denmark and introduced in Norway in 2015, not only highlight Norway’s ambition to ‘raise the quality’ of cancer care but are also a key tool in the quest to become ‘a model nation for
good patient trajectories’ (Norwegian Directorate of Health, 2016a: 2). The pathways were first launched to the nation in 2014 with considerable pathos by the Minister of Health and Care, who claimed that pathways had ‘grown out of patients’ stories and experiences…The integrated pathways are not a managerial signal from above. They are the patient’s managerial signal from below. The patient’s wish to us’ (Bent Høie, cited in Håland and Melby, 2017: 393). This message was followed up in the Prime Minister’s new year’s speech on 1 January 2015, where she spoke about Christmas and ‘feelings of loss and mourning, of losing someone, and of losing someone who has died of cancer’, adding ‘it is the responsibility of politicians to improve organisation of the health services, so that fewer people will have to lose someone they love to cancer’ (Solberg, 2015). Håland and Melby (2017: 392) identify how this affective rhetorical framing presents the pathway: first as something intrinsically good, and second that it involves people taking care of each other when we need it. These are two claims that we will look at in this article.

‘Integrated care’ is a broad concept, referring to a set of emergent clinical, organisational and policy changes aimed at improving service efficiency, patient experience and outcomes. A recent study (Hughes et al, 2020) attributes this broadness to misalignment between aspirations underpinning such models and their multiple application strategies, and concludes that integrated care programmes do not necessarily lead to intended changes in experience and outcome. Hence, we are at a critical juncture for reflecting on what constitutes quality in integrated cancer care at the experiential level. With the government’s rhetoric of experience-nearness to patients and next of kin and its denial of managerial motives, we were interested to see what an integrated cancer care pathway contains and how it relates to values held by White Paper 34, particularly those related to vulnerability. Our aim is to contribute to a critical discussion of what is at stake when it comes to quality in contemporary cancer care, in the light of recent shifts in Norwegian healthcare policy.

**Theoretical perspectives and methodology**

The value of ‘thinking in cases’ is that we can reason around a shared example (Forrester, 2017). Our case is based on policy and clinical guideline documents. Policy discourse may be studied as ‘a framework and a logic of reasoning that, through its penetration of social practice, systematically forms its objects’ (Alvesson and Sköldberg, 2009: 250). As such, discourses are not removed from reality, but ‘emerge from, and play a role in, the changing historical, political, and social context’ (Saukko, 2003: 99). Fotaki’s (2006) investigation of health policy discourse points towards its role in what we would call ‘the psychosocial imaginary’, which holds in tension the duality of life and death drives, thus serving a functional and symbolic role. A psychosocial imaginary is especially poignant for cancer policy, which so directly concerns attempts to manage a life-threatening disease. In practice-near Nordic contexts, psychosocial researchers have noted the impact of neoliberal governance policy on welfare and healthcare professionals (Salling Olesen, 2004; Andersen, 2005; Hjort, 2012; Dybbroe, 2013; Ramvi, 2017; 2011; Ramvi and Gripsrud, 2017), and patients (Hjort, 2015). A shared observation is that rising managerialism in public services has led to a devaluation of face-to-face relationships and a culture of intolerance for problems that cannot be solved.

Our analysis of the present case emerges from our understanding as researchers concerned with psychosocial and ethical conditions for professional relational work. We
are interested in dialectics between intra- and interpersonal dimensions, institutional practices and societal discourse, which all together are constitutive of conditions for welfare (Froggett, 2002; Cooper and Lousada, 2005). From a psychosocial perspective, the relation between the psychic and the social are seen as being irreducible to one another, and this complementarity means that one cannot exist without the other, although they are not the same (Hollway, 2008). For example, Cooper and Lousada (2005: 7–8) draw on object relations theory to argue that:

just as the infant benefits from, or is disabled by, the state of mind of their parents or carers so we believe the state of mind of society is reflected in the manner in which it provides care for its citizens…. The quality of this provision is a reflection of societal well-being or the lack of it.

According to these authors, a detrimental outcome of neoliberal governance is an emerging state of ‘borderline welfare’ resulting from attempts to manage contemporary social anxieties around, for example, dependency and loss. Borderline welfare facilitates or discourages particular forms of feeling, rather than supporting containment for what is hard to bear through the psychic function of what Froggett (2002) calls ‘protective social institutions’. One manifestation of such a new form of feeling is the shame induced in individuals (including healthcare professionals) who desire to achieve organisational ideals but feel insecurity, failure and inadequacy due to the incessant demands of neoliberal governance, which are enforced through a culture of performativity, which quantifies everything, including the self (Hoggett, 2017; Ramvi and Gripsrud, 2017).

An interlinking perspective is added to our analysis by a psychosocial understanding of the relationship between care and ethics (Hollway, 2006), which we conceptualise as ‘psychosocial care’. Despite its timelessness, caring is not a transcendent relational practice, as ‘norms surrounding both the giving and receiving of care, while dictated in part by the nature of human need, [are] also conditioned by cultural and ethical understandings and by economic and political circumstances’ (Kittay et al, 2005: 443). A psychosocial understanding of care is intersubjective. It does not delineate sharply between the one who provides care and the one who receives it, nor does it separate the individual from their relationships or societal context (Froggett, 2002; Hollway, 2006). The aim of psychosocial care is not to make a person autonomous and free from reliance on others, but rather to meet a primary need – as basic as our need to breathe – going beyond ‘the binary between autonomy, independence and the ethic of justice on the one hand and relationality, empathy and the ethic of care on the other’ (Hollway, 2006: 16). With these two perspectives informing our analysis of the case, we have come to question the value basis of the integrated breast cancer pathway and how it can be claimed to improve quality of care. However, in order to illustrate our concerns, we must first address the plight of breast cancer patients.

The experiences and needs of breast cancer patients

Breast cancer is the most common cancer in women in Norway. In 2018, breast cancer incidence was 3,629, and there are currently 49,344 women living in Norway who have had a breast cancer diagnosis at some point (Cancer Registry of Norway, 2019). Despite a good prognosis of survival, women may experience a breast cancer diagnosis
as a physiological, psychological and existential crisis (Arman and Rehnsfeldt, 2003), correlating with distress (Montazeri, 2008), post-traumatic stress (O’Connor et al, 2011) and major depression (Fann et al, 2008). Adjuvant treatments may add to the initial distress surrounding diagnosis and surgery, described by one breast cancer patient as a ‘snowballing’ of uncontrollable events (Gripsrud et al, 2016). As we build our case, we are thus interested in pursuing how the integrated pathway addresses care provision in a clinical context where affects are strong and patient–carer contact is structurally limited due to the rapid discharge of day surgery. In what follows, we first present a textual analysis of the breast cancer pathway guideline. On this basis, we subsequently discuss how the guideline’s dominant discourse of ‘individualised standardisation’ (Håland and Melby, 2017) challenges a psychosocial care understanding, where care and ethics are an intrinsic couple (Hollway, 2006) in professional relational work and in welfare as a whole (Froggett, 2002).

The integrated breast cancer pathway

‘The integrated breast cancer pathway’ was first published in 2015 and subsequently revised in 2016 in collaboration with clinicians and patient organisations (Norwegian Directorate of Health, 2016a: 2). It aims to secure an effective and holistic patient trajectory. The target audience is health personnel, managers and decision makers at different service levels. Its expert author group consisted of eight medical doctors, one nurse and one user representative. The pathway adheres to medical treatment standards specified in a separate comprehensive guideline (Norwegian Breast Cancer Group, 2018). Logistically, the pathway starts with reported suspected symptoms of breast cancer, whether after self-examination, mammography screening or consultation at the general practitioner’s surgery. Subsequent diagnostics then occur within seven days from specialist referral. Surgical treatment occurs within 13 days after the diagnostic evaluation. The total timeframe of the pathway is 24–27 calendar days.

The guideline consists of 18 pages, divided into the following chapters:

(1) Introduction.
(2) Entry into the integrated pathway.
(3) Diagnostic testing of breast cancer.
(4) Treatment of breast cancer.
(5) Follow-up and check-up of breast cancer.
(6) Trajectory times.
(7) Registration of codes.

Overall, the document concerns the timing of medical events in the treatment trajectory and multidisciplinary task distributions between hospital departments and medical specialties. Psychosocial concerns are briefly referred to in Chapters 1, 4 and 5. When we searched the guideline for the keyword ‘care’ (Norwegian ‘omsorg’), we found no references to it whatsoever, other than two mentions of ‘cancer care’ (Norwegian ‘kreftomsorg’). We then broadened our scope to include descriptions of care practices. We found the following statement in the introduction: ‘The aim is for patient and next of kin to experience good information, involvement, participation and dialogue through the whole trajectory. Patient and physician in charge make decisions together about the further trajectory’ (Norwegian Directorate of Health, 2016a: 4). And, further:
Communication with patient and next of kin shall, in all contexts, be based on respect and empathy. Information and dialogue shall take place in a considerate manner and be adapted to the receiver’s individual suppositions, like, for example, age, social situation, language, expressed wishes and needs. Furthermore, communication with the patient should include clarification concerning expectations about the trajectory, including involvement of patient and next of kin. Norwegian Directorate of Health, 2016: 4

The next paragraph signals a return to ‘communication’ and ‘information’, which must be ‘consistent and coordinated’: ‘As part of the communication, patient and next of kin shall be involved and informed about examination results and the next step in the integrated pathway. Interpretation services are used when needed’ (Norwegian Directorate of Health, 2016: 4). The last paragraph on page 4 states that: ‘Hospitals shall, in collaboration with relevant patient organisations, encourage conversations with approved patient advocates if cancer patients and/or their next of kin should wish so.’

To the extent that psychosocial care aspects of breast cancer treatment are addressed at all in the introduction, they are covered by these aforementioned passages, which repeat the following keywords: information, involvement, participation, dialogue, communication, respect, empathy, considerate manner, individual suppositions, clarification, expectations, expressed wishes and needs, consistent. ‘Communication’ (n = 4), ‘information/inform’ (n = 4) and ‘participation’ (n = 3) are the most-used terms (p 4). ‘Information and dialogue with the patient’ is a subheading used throughout the document’s chapters, in repetitive phrasing. Typically, the patient ‘is informed’ and ‘the patient receives’ information (for example, p 9). ‘Care’ is not articulated once in the introduction to the pathway.

In Chapter 4 (p 12), which is the most concerned with ‘care-like’ practices, we find the following under the subheading ‘4.3 Support treatment and nursing’:

[N]ursing shall be provided to accommodate the patient’s disease-specific problems and safeguard consequences of illness and treatment which impact basic needs. Next of kin’s need for information shall also be accommodated and necessary measures implemented. For example, such measures can contribute to the patient’s and [his or her] possible partner’s and children’s improved understanding of the disease’s impact on the patient’s functional ability and the impact of the treatment on body image and sexuality.

This extract concerns the only central depiction of nursing, constituting barely six lines in an 18-page document. ‘Basic needs’ are not described in detail, but the inference is that those needs can be perceived by the nurse and met with information. The next of kin’s needs are also described as information needs, meriting ‘necessary measures’ that can improve the family’s understanding of ‘the disease’s impact on the patient’s functional ability’. Suffering and psychosocial concerns are thus neglected, despite their prevalence in this patient group. These appear to be reduced to a non-detailed mention of ‘body image and sexuality’.

Care situations that may be emotionally challenging are described peripherally, as ‘support treatment’ to be conducted by nurses, whereas for doctors there is an emphasis on communication. For example, in section 4.5, a consultation is described
that takes place after diagnostics have been prepared. This is the moment when the patient is told that she has breast cancer:

The conversation clarifies the patient’s expectation of the trajectory. The patient’s life situation, possible anxiety, resources, needs and wishes are uncovered. The patient is encouraged to bring a next of kin/companion to the conversation. (pp 12–13)

Here, it appears to be sufficient to ‘uncover’ the patient’s anxieties, needs and wishes. The clinician is not expected to take measures to meet such needs. Of notice here is how the repeated reference to the desired presence of next of kin appears to tacitly signal a transfer of care responsibility from professionals to family or friends.

Chapter 5 presents a frame for the post-surgery discharge consultation. Here, we find vague reoccurring references to ‘preparation’, ‘expectations’ and ‘information’ (p 14). Again, there is an implicit understanding that the patient’s problems should not be raised, nor solved, in the here-and-now of the clinical check-up. ‘Possible psychological reactions’ are acknowledged, but there is no indication that clinicians should attempt to pre-empt or accommodate such reactions by providing considerate care in situ or administering a referral to care from other agencies (p 14).

On the basis of this analysis, we now wish to pursue the absence of care in the integrated breast cancer pathway as a telling blind spot, behind which there is likely to be a complex web of meanings. We do not claim to make an exhaustive investigation of all factors pertaining to this blind spot. However, in the discussion we want to draw on a psychosocial care understanding to indicate what may be at stake when care is discursively elided in healthcare policy.

**Discussion**

Let us recall the government’s ambitions to improve the quality of cancer care, based on patients’ needs, and to become a model nation for good patient trajectories, as well as its rhetorical framing of the integrated pathway as something intrinsically good and as something which involves people taking care of each other ‘when we need it’. Our reading of the integrated breast cancer pathway, a guideline for practice, reveals how these claims can hardly be substantiated. The document repeats ‘information’ and ‘communication’ as crucial signifiers for contact between health professionals and patients – with a tendency to emphasise the verbal transaction of facts. This emphasis implicitly suggests that the patient’s wellbeing is based on ‘knowing’, without problematisation of how difficult knowledge can be to convey at times, and that a clinician’s ‘informing’ does not always result in a patient’s ‘knowing’. To illustrate, previous studies have found that healthcare professionals refer to ‘conversations not had’, representing a failure in communication when a topic triggered uncomfortable emotions (Redwood et al, 2020); that doctors mask their ‘existential neglect’ of patients’ concerns by being ‘courteous but not curious’ (Agledahl et al, 2011); and that information in the doctor–patient relationship is unreliable, as telling lies is widespread on both ends of the relationship (Fainzang, 2016).

The guideline has one single reference to patient anxiety. This should be a red flag because cancer clinicians are frequently confronted with patients’ anxiety, and as professionals they must respond to it by using their own feelings as the basis for an
appropriate empathetic response (Ramvi, 2015). In this sense, the guideline illustrates how contemporary policy directions for professional care delivery frequently ignore the fundamental dimensions of their ‘affective work’ (Hjort, 2012).

Although ‘information’ is a key concept in the guideline, we argue that what is outlined goes beyond information sharing. Clinicians are expected to respond to patients’ individual differences, wishes, needs and expectations – a skill requiring relational competency, as they must stay emotionally attuned in order to be empathic and respectful at all times. These qualities are presented as something ‘one is’ (transcendent) rather than something ‘to be worked at’ (experientially). Likewise, ‘communication’ is not a mechanical delivery of information, but something to be worked at in the relationship. The guideline’s wording is highly condensed and does not go into explanatory or exemplary detail. For example, references to ‘language’ and ‘social situation’ do not concretise real-life issues concerning disability, non-native speakers or poverty. To us, the guideline’s formulation on ‘expressed wishes and needs’ evokes its opposite, as clinicians are frequently consciously or unconsciously interpellated by patients’ unexpressed wishes and needs (Balint, 2000/1963) – but these are confined to elsewhere.

‘Communication’ is a key concept and practice within care, which clearly implies relationality. Our concern is that the guideline repeatedly presents communication as a one-way movement towards the patient, who is left to her own devices in terms of her ability to absorb and act on the information. However, this would fall in line with the new national cancer strategy, where patients are offered an active role in their own treatment (Norwegian Ministry of Health and Care Services, 2018). The guideline enforces an assumption that knowledge is the patient’s most central concern and that information leads to coping. The notion that patients’ needs can be met by information, presupposes, as Fotaki (2014: 1276) argues, that patients are ‘rational individuals who, if given the necessary information, will make decisions that will maximise their welfare’. This is a prevalent understanding in health policy and services, which relates to the ‘application of rational choice theory to understanding agency in health care’ (Fotaki, 2013: 122), and an implicit view of the ‘the competent patient’ who has to be ‘well to be sick’ (Hjort, 2015). In the guideline, the patient is portrayed as a passive receiver of the professional’s information delivery exercise, thereby presupposing a universally autonomous, competent, resilient and rational cancer patient, rather than a particular human being with complex, and even irrational, feelings and who suffers in the face of a life-threatening illness (Gripsrud, forthcoming/under review). In this sense, rational choice theory is profoundly flawed as a measure to secure quality in care because it ignores the effect of the vulnerability that comes with ill health and does not consider in any depth the imperfections of the human mind in processing information (Fotaki, 2013: 122), nor the relational care needs triggered by vulnerability in illness.

This may be symptomatic of a larger societal problem. Layton (2009) claims that all citizens in neoliberal societies are encouraged to reject their vulnerability and that empathy may be jeopardised as a result. It is tempting to compare the guideline’s communicative one-way movement with Layton’s (2009: 109) psychodynamic ideal of a ‘two-way empathy’ – as ‘a state in which the one who does not seem to suffer would feel called upon to acknowledge some complicity in our commonality with the suffering of the other’. In contrast, the guideline refers to empathy without further extrapolation; it is simply a ‘default requirement’ in all communication. For
clinicians, a state of ‘two-way empathy’ is a precondition for providing appropriate care in an attuned response to patients’ needs. In this sense, caring is risky because it is a mutually vulnerable practice (Ramvi, 2011). Without a language for feelings, professionals may be more likely to act out unconscious agendas, with detrimental consequences for quality in care.

How can we account for the split between the government’s good intentions and the absence of a caring mentality in the integrated breast cancer pathway, which has been offered as a key tool for increasing user orientation? Fotaki (2017: 181) claims that concepts such as user orientation rely on and tap into ‘unconscious dynamics and fantasies of invincibility while ignoring the precariousness of life and our infinite potential to experience vulnerability’, with severe consequences for organisations and corruption of ‘the moral institutional fabric’. In the sense that the overarching function of recent policy shifts is to streamline public services and make them more cost- and resource-effective, with quality as a confounding add-on, our case confirms Molina-Mula et al’s (2018) claim that healthcare institutions and management increasingly correspond to a model of ‘market ethics’. Because market ethics may be a hard sell in welfare societies like Norway, it may suit the government to opt for extravagant rhetorical presentations, emphasising policy shifts as gifts to patients. As a branding exercise, these appear successful: the public’s impression of cancer care is more positive – although interestingly, the quality of cancer care has not improved (Norwegian Ministry of Health and Care Services, 2018).

Our case points to a concealed emotional reality: when ‘government abdicates responsibility for containing anxiety and for “holding” the vulnerable and the needy, dependency becomes more and more shameful’ (Layton, 2010: 367). Vulnerability and dependency are part of the human condition constitutive of all relationships and, importantly, cannot be willed away by policy (Vetlesen, 2009). As an antidote to abdications of responsibility in public healthcare, Fotaki (2017: 181) argues for a psychosocial approach and proposes ‘an ethics of relationality and compassionate care for the unknown “other”’. Such an ethics would include supporting professionals’ reflexive consciousness of the existential aspects of care, which we pursue in the following.

In their review, Hughes et al (2020: 1) state that ‘[p]olicymakers should critically evaluate integrated care programs to identify and manage conflicts and tensions between a program’s aims and the context in which it is being introduced’. In the clinical context relevant to our case, breast cancer patients face surgical treatment within two weeks of diagnosis, a period characterised by disbelief, distress and shock. During this time, patients experience difficulties with taking in information, let alone making choices on surgical treatment (author’s own (in manuscript, A); Gripsrud et al, 2014; Gripsrud et al, 2016). Although such severe states of mind can clearly be a complicating factor in consultations, they are not addressed by the guideline – indicating the need for a critical evaluation of its aim to secure a holistic patient trajectory.

Why should we be concerned by this? Hollway (2006: 52) describes good care provision as being ‘based on accurate understanding of the emotional expression of a need’. A psychosocial understanding of professional relational care – as a moral imperative, an ideal of quality and a lived reality – is that caring is not a transcendent given; it is informed by the professional’s self-understanding, shaped in turn by life and work experiences, and the sociocultural context (Ramvi, 2015), which includes
policy frameworks for the practice fields. Moreover, professional relational care requires ‘use of self’ and the possibility and ability to reflect on situated experiences at work (Ramvi, 2015; Ribers, 2018a). What this means is that in order to engage in therapeutic alliances (even in somatic medicine), professionals need to be in touch with, and be able to think about, not only the patient’s feelings and needs but also their own reactions and emotions (Ramvi and Gripsrud, 2017). When healthcare policy promotes ‘integrated’ pathways while distancing itself from caring relations as a foundation in professional medical practice, its discursive distancing may be adopted by professionals unconsciously as an aid to protecting themselves from their own affects and vulnerabilities (Menzies-Lyth, 1960). Put more bluntly, an emotionally distanced, defensive and unreflective professional practice can find its justification in the integrated breast cancer pathway. A tacit demand to provide care, which could be another interpretation of the guideline, can easily be turned into an idealistic injunction for professionals to simply ‘be empathetic’.

We have suggested that entering into caring relationships is a precarious practice, where inner resistances may intertwine with external conditions and demands – an accumulation of which may indeed produce a failure of care. Because of this, we suggest that care – as a relational practice essential to healthcare, precisely because it can be so challenging – must be guarded against managerially motivated political reforms based on market ethics. But how can care be protected if it is not even articulated in clinical guidelines? Neoliberal governance, an intrinsic feature of contemporary Nordic welfare policy, is accused of being entrenched in an individualised competence-focused onto-epistemology (Hjort, 2015), exemplified by the emphasis on information delivery in our case. As such, it is unharmonious with a psychosocial perspective, which is founded on intersubjectivity. Moreover, it may also be unharmonious with longstanding values in the clinical practice field, especially in nursing (Gripsrud et al, forthcoming). A recent study identified discrepancies between governance agendas and healthcare professionals’ views on treatment trajectories as anchored in care (Skirbekk et al, 2018). Findings portrayed a ‘widening gap between the views of clinicians on one hand and managers on the other. Clinicians experienced a threat to their autonomy, to their professional ideals and to their desire to perform their job in a professional way’ (Skirbekk et al, 2018: 746). A widening gap between policy and the practice fields can put ‘ethical pressure’ on professionals (Ribers, 2018a) and exacerbate vulnerability. Ethical pressure refers to societal and organisational pressure on professional welfare practitioners, as opposing conflicts of interest emerge. When a professional feels incapable of adhering to fundamental ethical values because macro-level constraints limit conditions for caring practice, it can lead to moral distress (Ribers, 2018b; 2019). Moral distress implies guilt on an existential level because professionals who are unable to provide quality care experience their work as morally unacceptable (Ribers, 2018a). If policy makers frame working conditions that are incompatible with the psychosocial needs of patients and the basic moral standards of caring professionals, they may harm professionals as much as patients. Under such conditions it is imperative that professional ethics are retained to protect against policy-caused degradation of care (Ribers, 2018b). Ideal practice, represented by professional ethics, is not very evident in the guideline, making health personnel more susceptible to ethical pressure.
Concluding remarks

In this article, we have discussed what is at stake in contemporary breast cancer care when policy makers forget, ignore or expel care in guidelines for practice. Against this blind spot, we have argued that care, as a response to human vulnerability and dependency, must be a vital concept in, and an irreducible aspect of, welfare. We have relied on a psychosocial understanding of care and ethics as an inextricable pair, bound up with policy discourse as well as institutional and relational practices at macro, meso and micro levels – altogether constitutive of a healthcare professional’s ability to provide quality care.

In our view, the Norwegian integrated breast cancer pathway does not provide ‘integrated care’. It is a managerial process tool, fusing together two different agendas: on the one hand, to provide national standards for medical treatment; and on the other, to introduce a stipulated trajectory timeline that can be seamlessly integrated with performance outcome measures. We have argued that a different language is required to enable healthcare professionals to recognise and think about their work in cancer care, beyond delivering outcomes and one-directional communication. Without a language for caring, they may be susceptible to splitting the intersubjective dimensions of care from their professional role – as work for which there are no words, no time, no space. In contrast, when professionals can see themselves as contributing to a relationship with patients and are attentive to feelings that emerge, empathy may develop, thereby supporting a high-quality, holistic care practice.

The case illustrates how ethical tensions can arise between the values of the welfare state and the influence of neoliberal governance on healthcare policy and practice. We see this reflected in a policy discourse that confounds quality with efficiency. While White Paper 34 stipulates that healthcare services shall be there for us when we are at our most vulnerable (Norwegian Ministry of Health and Care, 2015–2016), we found little evidence of such an ethical sensibility in the integrated breast cancer pathway. On this basis, we raise our concern that the elision of care in this guideline for practice may jeopardise professionals’ moral awareness of mutual vulnerability in caring relationships, which is also the basis for empathy.

As we come to a close, we wish to indicate what is at stake. The Norwegian government has a stated ambition to raise the quality of cancer care and become an international role model for good patient trajectories. Our case gives reason to question the validity and soundness of this ambition. This is first because the case illustrates how the integrated breast cancer pathway tends to split off the reality of emotional challenges facing clinicians in their daily work – by not addressing them or by delegating them away from the clinic and away from professional responsibility. Second, the case is suggestive of detrimental ethical pressures placed on professionals as carriers of experiences and values that are inter-relational, when the reality of such experiences and values is repudiated in clinical guidelines that frame the practice field. What professionals are left with, then, in the absence of a protective professional ethics, is the undesirable option of contributing to the production of borderline welfare, which, in our consideration, is far from congruent with good-quality cancer care.

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Notes

1. ‘Quality of care’ may denote quality of medical treatment – the degree to which current cancer treatment trajectories save lives. However important, this is not our focus.

2. All quotations from Norwegian documents have been translated by the authors. We sought to retain the somewhat staccato characteristics of the original text.

3. One interpretation could be that the early trajectory consultations take place in a surgical context, where doctors are known to ‘cut to the chase’ and may wish to avoid engaging emotionally with patients for various reasons. However, this does not account for the absence of care in the guideline’s depiction of nursing, as care is still considered an imperative nursing task.

4. In Norwegian, integrated pathways are called ‘pakkeforløp’, connoting ‘gift’ or ‘package trajectories’.

Conflict of interest

The authors declare that there is no conflict of interest.

References


Hjort, K. (2015) Skal man være rask for at være syg? Om konkurrencestatens krav om en kompetent klient [Do you have to be well to be sick? On the competition state’s demands for a competent client], *Gjallerhorn*, 1(21): 82–95.


