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Balancing Risk and Care in High-Risk Pancreatic Cancer: Ethical and Psychosocial Challenges

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Abbreviations: PC: Pancreatic Cancer; HRIs: High-Risk Individuals; IRFARPC: Italian Registry of Families at Risk of Pancreatic Cancer; AISP: Italian Association for the Study of the Pancreas

Introduction

In recent years, research on pancreatic cancer (PC) has achieved substantial progresses, partially reshaping the natural history of one of the most lethal malignancies. The integration of highly specialized surgery, medical oncology, and structured multidisciplinary care pathways has contributed to a meaningful extension of survival in an increasing proportion of patients. Despite these advances, late diagnosis remains a critical issue. Early-stage PC (stage I) is still rarely identified in routine clinical practice [1]. Surgical resection followed or preceded by systemic chemotherapy continues to represent the only potentially curative approach and the sole opportunity for long-term survival [2]. However, only 15-20% of patients are eligible for surgery at the time of diagnosis [3], as the majority present with advanced disease.

These limitations have prompted the development of dedicated surveillance programs for high-risk individuals (HRIs), particularly those with hereditary or familial predisposition. In this population, the risk of developing the disease is estimated to be approximately eight to tenfold higher than that of the general population, although the absolute lifetime risk varies substantially across genetic subgroups and remains relatively low in some categories. This situation, in itself, already raises an initial ethical dilemma.

Over the past decades, multiple surveillance initiatives and international research consortia have been established to prospectively monitor enriched cohorts of HRIs [4-7], with the aim of detecting PC at a preclinical stage. Such programs have enabled the early detection of PC or premalignant lesions, primarily at baseline assessment but also during longitudinal follow-up [8-10]. In Italy, the Italian Registry of Families At Risk of Pancreatic Cancer (IRFARPC), established in 2015 and coordinated by the Italian Association for the Study of the Pancreas (AISP) has implemented an integrated model of multidisciplinary clinical management [11]. It has demonstrated to be a successful multicenter effort to detect early PC and identify genetic predisposition within a public national health system [12-14].

While surveillance represents a rational strategy for early detection, it also generates a distinctive existential condition: individuals who are clinically healthy yet fully aware of their increased risk of developing a highly lethal malignancy. This awareness may exert a profound impact on the psychosomatic dimension. The body becomes not only the object of periodic

monitoring, through magnetic resonance imaging with cholangiopancreatography and clinical evaluation, but also a symbolic locus of anticipation and anxious projection. Within this liminal space between health and disease, uncertainty may become chronic, potentially manifesting as functional symptoms, sleep disturbances, fatigue, and heightened somatic vigilance. Accordingly, surveillance for pancreatic neoplasia should not be conceived merely as a diagnostic intervention, but rather as a long-term relational process encompassing biological, psychological and ethical dimensions. In recent years, a growing body of literature has begun to systematically examine the psychological impact associated with the condition of "being under surveillance"[15-19]. In 2025, our group published a longitudinal study providing robust data on the psychological burden experienced by healthy individuals enrolled in PC surveillance programs due to familial risk, assessed 36 months after enrollment. The results demonstrated a progressive increase in psychological distress among HRIs over time [20]. These findings highlight that surveillance, while primarily intended to facilitate early diagnosis, is not psychologically impactful. Empirical evidence emphasizes the need to integrate structured psychological support within screening programs to ensure that oncological prevention does not impose an unrecognized psychosocial burden.

Within this framework, critical ethical and legal considerations emerge. In surveillance programs, informed consent must address not only the anticipated benefits of early detection but also the potential psychological impact over the medium and long term. Comprehensive disclosure requires acknowledging inherent uncertainties and discussing the possible emotional consequences of ongoing monitoring. True self-determination entails that individuals can evaluate both the biological risk and the existential implications associated with enrollment in such programs. In surveillance programs marked by rapid technological advances and a considerable temporal gap between an individual's current health status and the potential onset of disease, it is essential to complement diagnostic tools with processes of progressive reflection and advance care planning [21]. Within this framework, shared care planning can serve as a dynamic, interactive forum for dialogue, enabling the continuous integration of clinical information, personal values, and psychological resources. This approach supports adaptation to the evolving clinical and existential circumstances of each individual. Integrating empirical evidence on psychological distress among individuals under surveillance with legal considerations of self-determination and palliative care models that emphasize comprehensive, patient and team-centered care allow for the conceptualization of a broader, and inherently more complex, paradigm. PC surveillance should not be understood solely as a diagnostic procedure, but rather as an extended relational process. It is precisely within this temporal and symbolic expansion of the "time of care" that the most salient ethical challenges arise. The first ethical concern pertains to the principle of non-maleficence. Enrolling individuals who are currently healthy, albeit at high genetic or familial risk, into a surgical-radiological surveillance program exposes them not only to repeated diagnostic procedures, but also to a demonstrable psychological burden. Notably, the scientific community has yet to establish a specific term to describe individuals undergoing such surveillance who cannot be considered patients, but rather potential future patients. Surveillance may, in effect, become a form of "medicalized anticipation," whereby an individual's identity is progressively reframed as that of a "potential patient". This diagnostic foresight carries the risk of fostering an existential anticipation of illness: individuals may begin to live as though cancer were already present, even in its absence. Such a state of sustained vigilance can influence personal decisions, life planning, and family and professional relationships, rendering the boundary between preventive care and the induction of psychological suffering remarkably narrow.

The second ethical concern pertains to the principle of proportionality. Although the prognosis of PC has improved, it remains generally poor. Even when diagnosed at an early stage, there is no guarantee of definitive cure, and the clinical course may still involve major surgical interventions, systemic therapies, and potential complications. Given that a substantial proportion of cases ultimately result in an unfavorable outcome, the ethical concern becomes particularly acute, as it calls into question the justification for subjecting a large cohort of healthy individuals to prolonged surveillance that, for many, may generate anxiety without providing direct clinical benefit. This consideration does not undermine the value of early diagnosis but rather highlights the need to define a risk threshold that renders the intervention ethically defensible. In this context of uncertainty, the psychological dimension must be recognized not as a marginal side effect, but as an integral component of ethical evaluation.

The third ethical consideration concerns authentic self-determination. For an individual's decision to enter or remain in a surveillance program to be genuinely voluntary, they must be fully informed not only of potential clinical benefits but also of empirical evidence regarding psychological distress observed over time. Only under such conditions can consent be considered truly informed. Absent this comprehensive disclosure, there is a risk of "preventive" paternalism, whereby the emphasis on clinical benefit obscures the complexity of the individual's lived experience. An additional ethical concern emerges when a surveillance program does not systematically incorporate structured psychological support: in such cases, a disparity arises, whereby resources are invested in early detection but not in safeguarding the mental well-being of participants. Based on the available evidence, the integration of psychological care pathways cannot be considered optional; rather, it should constitute an essential component of the protocol, equivalent in priority to radiological assessments. Being "under surveillance" becomes a component of one's personal

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narrative. Surveillance should therefore be recognized as a not neutral procedure, but as an intervention that shapes identities and ascribes meaning. The palliative care approach provides a robust framework for addressing these challenges. By prioritizing person-centered care, quality of life, and the integration of psychological, relational, and clinical dimensions, it emphasizes the importance of supporting individuals not only in therapeutic decisions but also in navigating the uncertainty that may precede disease onset. Even in preventive contexts, this perspective highlights the critical role of transparent communication, shared decision-making, and the systematic inclusion of psychological support as core components of ethically responsible surveillance programs. We must not underestimate that, alongside the care of individuals under surveillance, equal attention must be devoted to supporting the well-being of healthcare professionals. High-complexity clinical and emotionally demanding settings, such as pancreatic surgery and the management of high-risk patients, expose practitioners to chronic stress, moral conflicts, and ethical challenges [22]. The combination of severe prognoses, decisional uncertainty, and relational demands can contribute to burnout and depersonalization, with significant repercussions for the quality and safety of patient care.

Caring for healthcare providers is essential in contexts of high clinical complexity. Recognizing their subjectivity and professional emotional competence not only safeguards their mental health but also supports the development of professional identity and ultimately enhances the overall quality of care.

Consistent with Dejours' insights [23], acknowledging the work performed enables the attribution of meaning to the efforts, uncertainties, and anxieties inherent in clinical practice, serving as a critical protective factor for both provider well-being and the sustainability of care systems. Through regular supervision and case review sessions, encompassing emotional, relational, and ethical dimensions, the clinical team can transform individual experiences into shared knowledge, mitigate conflicts, and promote a positive, sustainable work environment.

Ultimately, effectively addressing the psychosomatic dimensions and ethical challenges inherent in the care of individuals at high risk for PC requires acknowledging that oncological prevention is a complex, holistic process. It engages the individual in their entirety and demands care systems that integrate scientific evidence, legal frameworks, and humanistic considerations. This issue is particularly salient in the context of precision medicine and increasingly technologized healthcare, where the need to attend to individual well-being and to care for the person as a whole becomes a central ethical priority. Only by systematically embedding mental health support within surveillance programs and concurrently sustaining the well-being of the healthcare professionals involved, can we establish care pathways that are ethically sound, clinically effective, and truly sustainable over time.

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