The Tale of Quaternary Prevention: How Partnering with Patients Leads to a New Approach to Prevention.

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Abstract

In the mid-20th century, clinical prevention mainly focused on the disease and its progression. However, the emergence of person-centered care, physician-patient partnerships, and increased awareness of the potential harms of medicine has led to a new concept of prevention. This concept, which is already widely taught in Family Medicine and available in multiple languages, views medicine as a co-construction between patients and doctors, prioritizes the partnership relationship between the physician and the patient, and acknowledges that medicine itself can be a potential source of health problems. The authors suggest revising the Medical Subject Heading (MeSH) terminology to include the four proposals of the World Organization of Family Doctors (WONCA), including quaternary prevention under its original definition that implies an ethical stance and a patient-doctor partnership, rather than just a quality assurance approach.

The growing movement of person centered care

The concept of person-centered care has gained interest within the field of family medicine since the middle of the 20th century. This approach places a strong emphasis on catering to the individual needs, values, and preferences of patients. Key contributors to the development of person-centered care include figures such as Paul Tournier, who advocated for a holistic approach to healthcare that addresses physical, emotional, and spiritual needs [1], and Michael Balint, who emphasized the importance of exploring the psychological dimensions of illness and promoting effective doctor-patient communication [2]. Levenstein and his colleagues [3] emphasize the importance of physicians understanding not only the disease but also the patient. They introduce the concept of the two agendas, one belonging to the physician and the other to the patient. This approach involves taking the time to understand the patient's expectations, emotions, and concerns, in addition to their medical condition. The patient's agenda includes their health concerns, goals, and preferences. The doctor's agenda includes their medical knowledge, expertise, and treatment options. The key to successful patient-centered care in the Levenstein model is for the doctor to collaborate with the patient to understand and incorporate their agenda into the treatment plan. Jan McWhinney utilized patient-centered interviewing techniques to better understand patient concerns [4], while France Légaré conducted research on shared decision-making [5] and Paul Barr emphasized the importance of building strong relationships with patients and taking a collaborative approach to healthcare decision-making [6].

The evolution of person-centered care reflects broader linguistic and philosophical developments, with thinkers such as Wittgenstein highlighting the importance of language use and social context in shaping meaning [7].

Person-centered care involves employing strategies such as shared decision-making, patient education and technology to facilitate communication and collaboration between patients and healthcare providers. Evidence Based Medicine must provide a balance between scientific knowledge, physician and patient shared expertise of illness [8]. Continuity of care, which involves providing ongoing care by the same healthcare provider or team of providers, is also an integral component of this approach.

The concept of medical nemesis, introduced by Illich, has also influenced the development of person-centered care by highlighting the potential harms of medical interventions and the importance of weighing risks and benefits [9]. From ethical point of view, it is important to mention the Declaration of Kos, a renewal of the Hippocratic oath initiated by the French general practitioner Dr. Jean Carpentier, in the 1980s [10]. The first words of this declaration are "Never to forget that progress in our science requires us to listen to the person next to us" which is in line with the concern to establish a relationship and therefore a partnership with the patient. Ultimately, the goal of person-centered care is to provide comprehensive, compassionate care that caters to the unique needs of each patient, taking into consideration their ecological, psychological, and social environment.

The concept of prevention, from a disease-based to a person-centered vision

During the 1950s and 1960s, Leavell and Clark introduced the concept of prevention in the field of public health, which centered around two key variables: time and disease [11]. This concept is based on a linear approach, which revolves around the disease and draws from Clarke's study on the progression of syphilis.[12]. The terms "primary," "secondary," and "tertiary" were adopted from the stages of a disease and applied to patient care, education, and public health. Since then, clinical prevention has been viewed as a medical intervention that can occur either before or after the onset of a medical condition. (Fig.1)



Figure 1: The chronological and disease-oriented view of preventive activities along the lifeline is divided into three stages, which are derived from Clark's work on syphilis (1954). A fourth stage was later introduced by Jacques Bury (1988) for palliative care.

The Medical Subject Heading terminology (MeSH) employs the term "Primary prevention (P1)" to describe preventive measures taken before the onset of any medical condition, which includes health education and promotion. The role of "Secondary prevention (P2)" is somewhat ambiguous and is occasionally utilized by cardiologists to refer to preventative measures following an event. "Tertiary prevention (P3)" is not widely utilized, and "Quaternary prevention" has been proposed for palliative care by the Belgian psychiatrist Jacques Bury.[13]. This approach that prioritizes the medical condition and places the patient as the object of care along the timeline is known as a disease-oriented approach.

Over time, the international general practice movement has gained momentum, and a new vision of prevention has surfaced, placing emphasis on the doctor-patient relationship and recognizing the risks involved in medical interventions. This evolution has led to the development of the concept of quaternary prevention (P4).[14]. This concept aligns with the Levenstein model of patient and doctor agenda by promoting an ethical partnership between patients and doctors to collaboratively make medical decisions and prevent unnecessary medical interventions. However, the P4 concept has been subject to various interpretations, and as a result, its original meaning has been distorted. It has even been included in the MeSH terminology under a different definition than its original one.

The original model, which is based on a 2x2 cross-tab (Fig. 2), illustrates prevention as the outcome of the relationship between patients and doctors. Doctors aim to identify diseases, while patients may eventually experience symptoms. The 2x2 cross-tab model depicts four activity fields, with naturally blurred boundaries, along a timeline. In this perspective, the timeline intersects the two-fold table. Working along this timeline is a fundamental aspect of the family doctor's role throughout the patient's life. Ultimately, patients and doctors will come together at the end of this timeline, facing suffering and death together at point Ω .



Figure 2: The various stages of prevention are collaboratively developed by the doctor who seeks to identify diseases and the patient who desires good health. As a result, the timeline is now slanted. The patient and doctor will eventually encounter each other in times of illness and at the end of life, represented by the point Ω . (Jamoulle 1986)

First do not harm

The primary objective of this article is to promote the precautionary principle that is embedded in the concept of quaternary prevention. It aims to provide an explanation of the concept's origin and to emphasize the distinctions between the definition currently adopted by the MeSH and the original definition.

However, discussing quaternary prevention without revisiting the first three forms, published in 1995 in a Glossary of Family Medicine [15] and later supplemented by the fourth form in 2003 in the Dictionary of General Practice [16] by the World Organization of Family Doctors (WONCA), is not feasible.

The GP/FM definition of prevention focuses on the idea that prevention is not just a set of procedures or interventions, but rather a process that involves the patient as an active participant in their own health. This collaborative approach allows for a more personalized and effective approach to prevention. This implies that patients and doctors work together to determine the best course of action for the patient's health, taking into account cultural values, beliefs, knowledge, and technology.



Figure 3: The situation depends on the degree of certainty and agreement. Far from agreement crossed with far of certainty leads to chaos (Diagram attributed to R. Stacey (agilecoffee.com)

The P4 diagram resembles the Stacey diagram [17] in that it intersects the provider's level of certainty with the client's level of agreement (Fig. 3). When the provider's uncertainty intersects with the client's disagreement, it creates a pathway to chaos. Uncertainty and agreement are critical issues in the healthcare sector. The uncertainty regarding the effectiveness and safety of vaccines or treatments for diseases, including SARS-CoV-2, has resulted in a lack of consensus between patients and healthcare providers, ultimately leading to chaos in the healthcare system. This chaos is further exacerbated by the proliferation of conflicting information on social media platforms, which can contribute to the spread of magical thinking and peremptory propositions, ultimately leading to further confusion and misinformation. As such, it is important to address uncertainty and establish clear lines of communication and trust between patients and healthcare providers to promote effective

prevention and treatment strategies.



Figure 4: The 2x2 crosstab model introduced at the 1995 WONCA World Conference in Hong Kong divides GP/FM activities into four areas based on patient-doctor relationships, including preventive activities across the timeline. Quaternary prevention, which encompasses avoiding overmedicalization and protecting patients, is more than just a factual activity, but a way of thinking that can be applied to all areas of GP/FM. This concept also includes the limits of medical care and considers the needs of underserved populations, including undermedicalization.

Long Covid Patients: Stuck in Field Four of the 2x2 Crosstab Model.

Long Covid, also known as Post-Acute Sequelae of SARS-CoV-2 infection (PASC), is a relatively new and poorly understood phenomenon that has emerged as a result of the COVID-19 pandemic. It is characterized by a range of symptoms, including fatigue, shortness of breath, cognitive impairment, procedural memory loss and other issues that persist for months or years after the initial infection has resolved. Patients with Long Covid often report difficulty in obtaining a proper diagnosis or treatment, as the condition does not fit into any pre-existing diagnostic criteria or disease models. As such, they may find themselves stuck in the fourth field of the 2x2 crosstab model, where they receive excessive testing and interventions that may not address their underlying symptoms. It is essential that healthcare providers recognize and address the challenges faced by Long Covid patients, including the need for new diagnostic and treatment approaches that are tailored to this emerging condition.

The practice of medicine, particularly in the context of Covid and Long Covid, is often challenged by the complexity and uncertainty of the disease. Rational decision making is difficult when faced with a constantly evolving and poorly understood illness that can present with a wide range of symptoms and long-term complications. This can lead to a sense of chaos in the healthcare system as healthcare providers struggle to keep up with new information and adjust their practices accordingly. However, it is important for healthcare providers to continue to work collaboratively with patients and engage in ongoing research to improve our understanding of these conditions and provide the best possible care for affected individuals. Similar to chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) or post-viral fatigue, doctors often find it frustrating when they cannot easily diagnose or categorize patients with Long Covid into known medical classifications [18].

The absence of gate-keeping in Belgium enables patients to directly consult with specialists they deem appropriate, based on their own perceptions. This approach has resulted in catastrophic outcomes, as evidenced by the diagnoses documented in the medical records of Long Covid patients before their condition is correctly identified. (Fig 5).

things include the second seco	Cardiologist Neurologist Pneumologist	Angina pectoris (suspected) Alzheimer (suspected) Pulmonary embolims (suspected) Hyperventilation
Hard Hard Hard Hard Hard Hard Hard Hard	Rheumatologist	Fibromvalgia
anymore Ogens Stor dizzines	Psychiatrist	Traumatic shock
seep forgets		Professional exhaustion
heart a plant of the state of t		Anxiety attacks
feels a constitution brain		Post traumatic stress disorder
3 2 Chest coughing		Depression
depressed and WOLOS	A teacher	Lazy teenager
day could bit lerance contractions	Gastroentelologist	Irritable bowel syndrome
triggers SSENSE malaise	-	Functional colopathy

Patient's agenda

Doctor's agenda

Figure 5: Left; word cloud of the symptoms expressed by 34 patient with clinical Long Covid syndrome. Right; diagnostics found in the medical records of the patients, Belgium July 2021 - June 2022 [19]. All 34 patients diagnosed with PACS (Long Covid) reported that the specialists they consulted failed to listen to their concerns and provided inaccurate and speculative diagnoses based solely on their individual areas of expertise.

Long Covid is a complex story of medically unexplained symptoms and medical wandering. The patient who is suffering may feel helpless, abandoned, desperate, and frustrated when doctors are unable to diagnose their condition or dismiss it as outside their area of expertise. It can be a frustrating experience for both patients and healthcare providers.

Helen Atherton and her colleagues stated that "the patient-doctor relationship is vital in the management of people with Long Covid" [20]. The Long Covid phenomenon provides a chance to create a new research epistemology since it was the patients who initially recognized the condition and spurred healthcare providers to explore it further. Patients have been crucial to Long Covid research, actively increasing awareness and sharing their encounters with medical professionals. As a result, establishing collaborations between doctors and patients is crucial to progress medical research and enhance healthcare outcomes.

The GP/FM definitions of prevention

Let's redirect our attention from the customer-supplier relationship to the interaction between patients and doctors. The relationship between a doctor and patient goes beyond a mere exchange of products and services. It involves a reciprocal sharing of information, an empathetic acknowledgement of worries, and a collaborative attempt to confront ambiguity in the pursuit of medical care.

Here, we will analyze the four definitions as published in the WONCA dictionary [16] and link them to their corresponding uniform resource locator (URI) in the HeTOP multiterminological database [21]. The notion of clinical prevention in individual practice pertains to the micro level. However, the idea of quaternary prevention is also relevant to the meso level (education and care organization) as well as the macro level (public health and health policy).

Clinical prevention; the application of preventive measures. A field of medical practice composed of distinct disciplines that utilize skills focusing on the health of defined populations in order to promote and maintain health and well-being, and to prevent disease, disability, and premature death. Year introduced: 1995

1. **Primary prevention**; Action taken to avoid or remove the cause of a health problem in an individual or a population before it arises. Includes health promotion and specific protection (e.g. immunization) Year introduced: 1995

Secondary prevention; Action taken to detect a health problem at an early stage in an individual or a population, thereby facilitating cure, or reducing or preventing it spreading or its long-term effects (e.g. methods, screening, case finding and early diagnosis) Year introduced: 1995

- 2. Tertiary prevention; action taken to reduce the chronic effects of a health problem in an individual or a population by minimizing the functional impairment consequent to the acute or chronic health problem (e.g. prevent complications of diabetes). Includes rehabilitation. Year introduced: 1995
- 3. Quaternary prevention; action taken to identify a patient at risk of overmedicalisation, to protect him from new medical invasion, and to suggest to him interventions,

which are ethically acceptable. Year introduced: 2003

Patient feeling

_	No disease	disease
ſ	Primary prevention:	Secondary prevention:
healthy	Action taken to avoid or remo- ve the cause of a health pro- blem in an individual or a po- pulation before it arises. Inclu- des health promotion and spe- cific protection (e.g. immunization).	Action taken to detect a health pro- blem at an early stage in an indivi- dual or a population, thereby facili- tating cure, or reducing or preven- ting it spreading or its long-term effects (e.g. methods, screening, case finding and early diagnosis).
	Quaternary prevention:	Tertiary prevention:
sick	Action taken to identify a patient or a population at risk of over medicalisation, to protect them from invasive medical interventions and provide for them care proce- dures which are scientifically and medically acceptable	Action taken to reduce the chronic effects of a health problem in an individual or a population by mini- mizing the functional impairment consequent to the acute or chronic health problem (e.g. prevent com- plications of diabetes). Includes rehabilitation.

Doctor seeking

Figure 6: The three definitions of Primary, Secondary, and Tertiary prevention, which were already published in the WONCA glossary of GP/FM in 1995, align seamlessly with the 2x2 crosstab model. The fourth field, which was missing, was proposed as Quaternary Prevention at the 1999 Durham WONCA International Classification Committee (WICC) meeting. The definition was endorsed by the entire WICC group with a standing ovation and was included in the WONCA dictionary of GP/FM in 2003.[16]. The arrow shows the impact of the P4 concept on the whole practice. The arrow illustrates how the P4 concept has influenced the broader landscape of medical practice

A two fold table can be used to better understand the breadth and depth of these definitions.

It is worth noting that these definitions can be easily visualized in a two-fold table (see Figure 6). The table considers the relationship between the doctor and the patient, with primary prevention representing the true negative, tertiary prevention representing the true positive, secondary prevention representing the false negative, and quaternary prevention representing the false positive [22]. Quaternary prevention involves a mindset that goes beyond a mere factual activity. It encompasses a way of thinking about healthcare that can be applied in various domains, addressing issues such as overmedicalization resulting from overinformation, overscreening, overdiagnosis, and overtreatment. Additionally, it includes considerations about avoidable care, patient protection, and the limits of medical intervention. This field

also implicitly encompasses patients and populations who may be deprived of adequate healthcare, thereby covering under-medicalization as well.[23]. Quaternary prevention also addresses peculiar diagnoses such as; No disease disease - Medically unexplained symptoms - Worried well - Difficult patient - Functional somatic syndromes - Somatoform disorder -Abnormal illness behavior or Non disease disease (unlimited list)

Let's consider now the Medical Subject Heading definitions

First of all we can see that prevention is an abundant and time stamped concept in the MeSH database. The term $prevent^*$ retrieves 881 entries in the MeSH while the term *prevention* retrieves 12 entries of which we are retaining those;

prevention and control [Subheading]

Used with disease headings for increasing human or animal resistance against disease (e.g., immunization), for control of transmission agents, for prevention and control of environmental hazards, or for prevention and control of social factors leading to disease. It includes preventive measures in individual cases. Year introduced: 1966 1,433,532 citations in PubMed as for 2023/01/07

- 1. **Primary prevention**; Specific practices for the prevention of disease or mental disorders in susceptible individuals or populations. These include HEALTH PROMOTION, including mental health; protective procedures, such as COMMUNICABLE DISEASE CONTROL; and monitoring and regulation of ENVIRONMENTAL POLLUTANTS. Primary prevention is to be distinguished from SECONDARY PREVENTION and TERTIARY PREVENTION.Year introduced: 1979
- 2. Secondary prevention; The prevention of recurrences or exacerbations of a disease or complications of its therapy. Year introduced: 2009
- 3. Tertiary prevention; Measures aimed at providing appropriate supportive and rehabilitative services to minimize morbidity and maximize quality of life after a long-term disease or injury is present. Year introduced: 2009
- 4. Quaternary prevention;; Actions taken to protect individuals (i.e. persons/patients) from unnecessary medical interventions that are likely to cause more harm than good. Year introduced: 2020

Among the MeSH items, the term Clinical Prevention obtains 1,433,532 citations on January 7, 2023, a rate that drops dramatically with 177,714 citations for Primary Prevention, 22,496 for Secondary Prevention, 195 for Tertiary and 5 for Quaternary. We can see that the division of the concepts of prevention in the MeSH does not really work. In order to cover the reality of the action, it is necessary to resort to 32 occurrences of the concept Screening in the MeSH. A cat could not find its young so complex are the subdivisions

Let's consider the differences in each entries

- P WONCA(clinical prevention) versus P MeSH (prevention and control). Although the WONCA definition emphasizes skills, there are only minor differences between the two headings.
- P1 WONCA versus P1 MeSH Although the WONCA definition emphasizes skills, there are only a few distinctions between the two categories.
- P2 WONCA versus P2 MeSH and P3 WONCA versus P3 MeSH

To begin with, it should be noted that the distinction between MeSH P2 and P3 is not clear. While the terminology used is different, the goals are essentially the same. MeSH P2 defines actions taken after an event has occurred, not to prevent it, but rather to manage or mitigate its avoidable outcomes.

These two MeSH definitions cover the same reality, i.e. preventing complications and promoting rehabilitation. In fact P2 and P3 of MeSH both cover tertiary prevention. But cardiologists are so used to using aspirin after a heart attack that they use the term secondary in its temporal sense when in fact they are proposing this action to avoid a complication

• P2 WONCA

The implicit meaning of secondary prevention for family physicians is screening. The doctor thinks that the patient meets the risk conditions for a given event and proposes an action to prevent it, such as mammography or PSA testing. In a way, the doctor is betting on the disease in a patient who is still healthy.

• P4 WONCA versus P4 MeSH

The new definition introduced in 2020, which is partially inspired by the WONCA concept of quaternary prevention, strikes out two essential elements: First, that it is a co-construction between the patient and the physician, and second, that it is an ethical stance. Unfortunately, the authors of the P4 MeSH definition only retained the application of quality control on medical action. These authors reduced the ethical and relational content of the initial thinking to a simple proposal of a feedback loop on medical production, feedback that has become an essential element of productivist management.

Quaternary prevention, an ethical duty

Thinking about the doctor-patient system has evolved into the patient-partner concept, while Ilichian thinking has been one of the foundations of thinking about global warming [24]. We thus see that quaternary prevention, which concerns both the patient and the physician and is intended to be based on a relationship ethic, is the result of a broader and deeper reflection than the managerial approach adopted by MeSH. As stated by C.Tesser, "Quaternary prevention could be defined as the practical or technical actions and developments of ethical, attitudinal, epistemological, and political resistance against the excesses of iatrogeny, preventivism, and medicalization in professional and institutional practices." [25]

Our proposal encompasses not only a revision of the current MeSH terminology on quaternary prevention, adhering to the original WONCA definitions, but also a comprehensive review of the broader prevention lexicon used within the MeSH. Our suggestion involves taking a divergent approach from the dominant theme of this conference by redirecting our focus from the public health domain to that of clinical practice.

In light of this perspective, it is clear that the doctor-patient relationship is not simply a meeting of two individuals, but a complex interaction that is shaped by a range of factors beyond the purely biological. To provide effective medical care, doctors must understand and take into account these broader factors, and work collaboratively with their patients to develop a shared understanding of the patient's needs and goals. By doing so, they can help to ensure that medical interventions are ethical, appropriate, necessary, and effective, while avoiding unnecessary or harmful interventions that can result from a purely biomedical approach.

Ethics and funding

No conflict of interest

The Long Covid study (Fig. 5) has been accepted by the Ethics Committees of the University of Liege and the Katholieke University of Leuven

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