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COMMUNITY AS CARE: SOLIDARITY, WHOLE PERSON CARE, AND LESSONS FROM THE PEER MEDICAL FOUNDATION

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Whole Person Care (WPC) is, at its core, a relational practice, requiring attention to not only symptoms or diagnoses, but to the emotional, social, moral and existential dimensions of patients' lives. However, within contemporary healthcare systems—which prioritize efficiency, specialization, and quantifiable outcomes—the relational aspects of care are frequently marginalized. Healthcare providers committed to WPC often experience a dissonance between professional values and systemic incentives, creating a persistent tension between what is ethically desired and what is institutionally supported.

This structural misalignment has tangible consequences. Relational labour, emotional presence, moral reasoning, and engagement with lived experience are often undervalued or rendered invisible. Clinicians, educators, and health professionals committed to WPC may therefore encounter isolation, moral fatigue, and a subtle erosion of meaning over time. These efforts underscore a critical tension: while WPC emphasizes interconnectedness and holistic attention, its practice within fragmented systems can leave practitioners carrying both the ethical and emotional weight of care alone.

Addressing this tension requires more than individual resilience or reflective practice. Sustaining WPC necessitates engagement in forms of solidarity and community that extend relational care beyond the dyadic patient–clinician encounter. Community provides a collective scaffold in which relational and ethical work is shared, acknowledged, and sustained. Solidarity, in this context, is not merely a value or aspirational ethic; it is a practice through which care is reinforced, knowledge is co-constructed, and moral and emotional labour is distributed. Solidarity is not incidental to WPC, it is its animating condition. Without solidarity, WPC risks becoming a solitary moral burden carried by individual clinicians or isolated patients. With it, care becomes a shared ethical project—one in which the recognition of each person’s full humanity is sustained not by any one individual’s effort, but by a community committed to practicing it together.

Our engagement with the Peer Medical Foundation (PMF) exemplifies the potential of community to sustain WPC in practice. PMF is a peer-led community grounded in solidarity among people living with rare diseases and marginalized health conditions, and the clinicians, educators, and learners who care alongside them. It is neither exclusively patient-facing nor practitioner-facing; it is a shared relational space in which both are full participants. Its co-leadership model deliberately places patients, particularly those from rare and underserved disease communities, alongside healthcare professionals as equal voices in shaping priorities, agendas, and practices. This structure is not incidental but foundational; it enacts the belief that those most affected by illness hold irreplaceable knowledge. Within this environment, relational care is not only supported but co-produced, enabling healthcare professionals, learners, and peers alike to sustain the ethical, emotional, and practical dimensions of WPC over time.

Finding Community in Unexpected Places: Solidarity Beyond Traditional Hierarchies

Even when one is committed to WPC, finding community can be difficult. Medical personnel (physicians, nurses, and allied health professionals), who serve as a patient’s first point of contact, often lack the time, tools, or resources to facilitate connections that address the emotional, social, or spiritual dimensions of illness.

It was within this landscape that PMF emerged as an unexpected and vital site of community. PMF members share lived experience with a range of rare diseases and navigate the intersectionality of illness, socialization, gender, and race. Its peer-led structure enables marginalized perspectives to inform advocacy and practice, fostering democratic participation in shaping priorities, sharing knowledge, and co-creating support networks. Community within PMF is not simply the aggregation of individuals; it is relational and ethical, grounded in the shared recognition of vulnerability across physical, emotional, social, and spiritual dimensions of illness.

Solidarity emerges when the community acknowledges the totality of a person's experience. Medical narratives are enriched when emotional and mental responses, social and spiritual implications, and the lived realities of navigating illness are considered alongside physical symptoms. In rare disease communities, this practice of shared knowledge and advocacy allows for the development of collective expertise, self-awareness, and mutual support. Within PMF, relational care is co-produced. Patients, peers, and clinicians collectively sustain one another, demonstrating how solidarity can extend the ethical and practical dimensions of WPC beyond the clinical encounter.

What Nurtures—and Thwarts—Community and Solidarity

We have learned through our work that community and solidarity do not emerge accidentally. They are cultivated through deliberate relational practices that resist the dominant rhythms of healthcare. One of the most essential of these practices is slowness and presence. In contrast to clinical environments shaped by time scarcity and productivity metrics, PMF creates space to slow down and attend fully to one another. This slowness allows people to be encountered not as cases or problems to be solved, but as whole persons whose experiences deserve careful listening. Scholars of narrative medicine emphasize that attentive presence and narrative exchange foster moral recognition and relational trust [1], particularly in contexts of illness and vulnerability. We have witnessed how simply making time to listen, without interruption or agenda, becomes an act of solidarity.

Another practice that nurtures community at PMF is valuing lived experience as knowledge. Members are encouraged to share personal narratives of illness, care, and marginalization. These narratives are treated as legitimate and instructive forms of expertise. This stance directly challenges what philosophers of medicine describe as epistemic injustice [2], wherein patients' testimonies are discounted due to structural power imbalances. By centring lived experience, PMF creates a space of epistemic justice where people who are often silenced within healthcare systems are recognized as knowers. This recognition not only affirms dignity but also deepens solidarity by redistributing authority across differences.

Marginalized members often bear greater emotional and social risk when speaking openly, particularly around experiences of racism, disability, or rare disease neglect. Without explicit attention to power and inequity, communities risk reproducing the very harms they seek to resist. As theorists of solidarity argue, it requires a willingness to sit with discomfort and to confront structural injustice rather than bypass it.

Solidarity within PMF is further sustained through mutual accountability. Because the community is peer-led, responsibility for care is shared rather than delegated. Members show up for one another, follow through on commitments, and remain attentive to the relational impact of their actions. Within PMF, this reciprocity is not incidental but constitutive—it is precisely because members hold one another accountable that trust deepens, and solidarity endures. In this context, solidarity remains an ongoing practice, one that requires attentiveness, maintenance, and care.

How Our Understanding of Community and Solidarity Has Evolved

Initially, we understood community primarily as a source of belonging and emotional support. Community meant not being alone and having others who could recognize and validate experiences of illness that were otherwise invisible. This understanding aligns with much of the peer support literature, which emphasizes shared experience as a foundation for connection and coping, particularly in rare disease contexts. At this stage, solidarity felt synonymous with empathy and mutual understanding.

Over time, however, our involvement with the PMF reshaped this understanding. Community came to feel less like a refuge and more like a shared responsibility. Solidarity was no longer only about feeling with others but about acting with them. Members did not simply offer support, they co-created responses to systemic barriers, advocated together, and shared the labour of sustaining one another. This shift mirrors relational ethics frameworks that emphasize interdependence, moral responsibility, and collective care. Through engagement with PMF, we have come to appreciate that community is an active, co-constructed space in which solidarity is practiced daily. It emerges through shared vulnerability, ethical engagement, and attention to the totality of lived experience, including physical, emotional, social, and spiritual dimensions.

Perhaps most significantly, practicing WPC within a community transformed our sense of who provides care. Care was no longer unidirectional or professionalized; it flowed reciprocally between peers, patients, and practitioners. Within PMF, solidarity is enacted when members recognize the moral, emotional, and practical labour involved in caring for oneself and others. Observing and participating in these interactions highlighted how solidarity requires not only attention to similarity but a deliberate willingness to engage with difference. It is in this engagement that ethical growth, relational depth, and moral resilience are cultivated—qualities essential to sustaining WPC

Finally, we have learned that WPC is not a solitary endeavour. Its principles are realized through relational practice embedded in the community. The work of sustaining ethical, relational, and holistic care depends as much on shared accountability and co-created knowledge as it does on individual skill or intention. Through PMF, we have witnessed that community and solidarity are not mere adjuncts to WPC; they are its scaffolding, enabling care to be ethically, relationally, and holistically sustained. Building this scaffolding requires humility and willingness—to be changed by relationships, to follow as readily as to lead, and to allow those most affected by illness and inequity to guide direction and meaning. Solidarity, in this sense, is not a fixed achievement. It is something we continually choose: a daily practice of showing up, listening without agenda, and remaining open to transformation. WPC is ultimately sustained not by individual habit or professional attitude, but by communities committed to practicing care, together. ■

References

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Biographical Notes

Salvatore Rotolo is an artist, lifelong learner, and advocate. He has lived experience with disability. As Director of Research, he guides projects to deepen knowledge on topics such as health equity, patient voice, and community-centred approaches to care.

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Leah Sarah Peer is the Founder and Executive Director of the Peer Medical Foundation (PMF), a youth-led nonprofit advancing health equity, inclusivity, diversity and racial justice in medicine. Drawing on her experience as a rare-sibling, and her formation within clinical and academic medicine, she brings an intersectional lens to rare disease education, health equity advocacy and the design of inclusive healthcare systems, guided by the conviction that transformative change in medicine begins when lived experience is not consulted but centred.