Title

Who is your Ideal Peer Mentor? A Qualitative Study to identify Cancer Patient Preferences for a Digital Peer Support App

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Abstract:

Purpose: Peer support can provide many benefits to cancer patients. However, sustained use of one-on-one peer support requires a good match between patient and peer mentor. Using an artificial intelligence (AI) matching algorithm has the potential to improve peer matching by achieving complex, preference-based matching. Therefore, using stakeholder co-design, this study identified patient preferences for peer matching criteria and other features of OpalBuddy, a digital peer support service to be developed within the Opal patient portal.

Methods: Patients using the Opal app were recruited, and semi-structured individual interviews were carried out with eight available women cancer patients. Qualitative data analysis followed an iterative and collaborative thematic analysis approach, using computer-assisted software (NVivo).

Results: Three themes, with supporting sub-themes, that describe patient preferences for matching with an ideal peer mentor were identified.

Theme 1. An ideal mentor can provide support at multiple levels, with sub-themes describing the levels: A. Sharing illness experiences, B. Practical information support, C. Emotional support, D. Social management coaching.

Theme 2. The ideal mentor has similar lived experience, with sub-themes describing the type of lived experience: A. Similar clinical situation B. Similar socio-demographics C. Interpersonal affinity.

Theme 3. The ideal peer mentor will be supported in their role, with sub-themes describing support options: A. Formal or informal training, B. General guidance, C. Supportive supervision.

Finally, based on different support needs (practical vs emotional), it was found that patients had varying, even opposing, expectations from a mentor's interpersonal communication style (solution focused vs good listener).

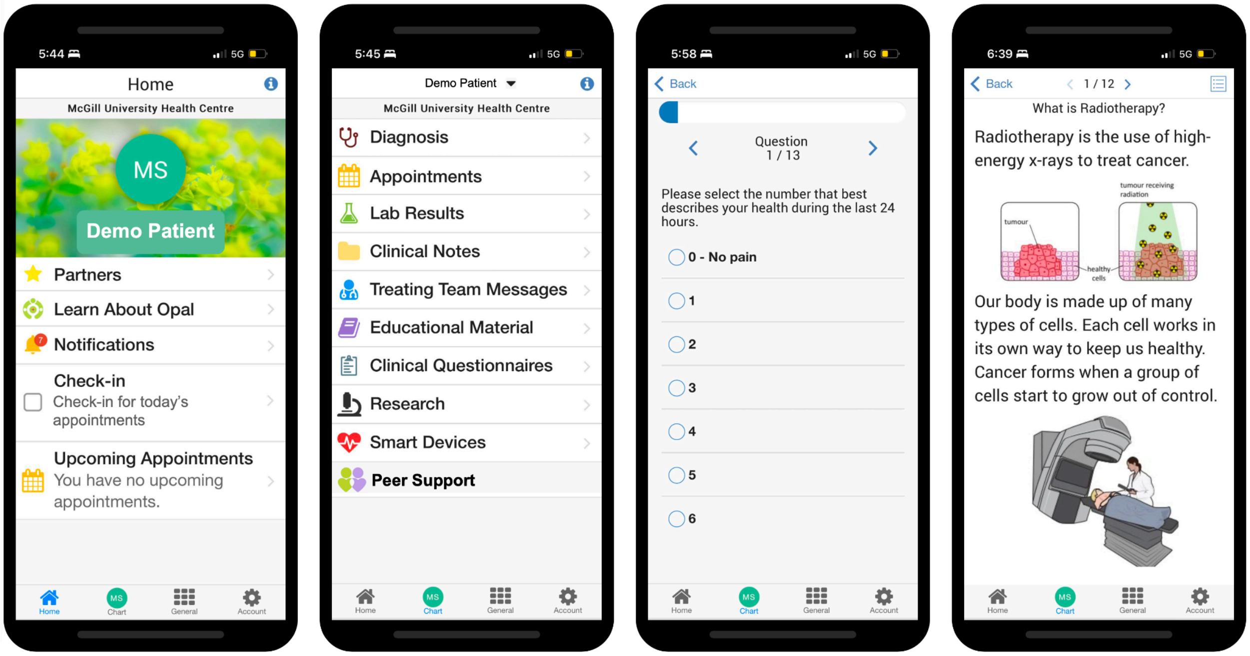
Conclusion: Patient preferences for an ideal peer mentor were identified through semi-structured interviews with a sample of eight women with a diverse set of cancers. Findings will be used to guide further work, including a similar study with men and a pilot study of a digital patient matching service for peer support in the open-source Opal patient portal.

Keywords: peer support; peer matching; cancer, mentor; semi-structured interviews.

Introduction

The cancer experience presents patients and their caregivers with many medical, logistical, and psychosocial challenges. Peer support is one way to reduce the uncertainty caused by these challenges [1]. By drawing on their own illness experiences, one cancer patient can act as a mentor to another patient, providing practical information and/or emotional support [2]. Peers' guidance complements, but never replaces, advice from professionals. And peers' lived experience with cancer makes their support distinct from informal support provided by a patient's existing social network (family/friends). Multiple systematic reviews show peer support provides practical, emotional, and health benefits to cancer patients [3,4], such as increased patient empowerment [5], reduced anxiety and depression, and improved quality of life [6–8]. However, reported benefits are limited to patients who access and remain in a peer support program, while most cancer patients may never access peer support in the first place [9], and an estimated one third of patients drop out of peer support services for failing to meet their support needs [10,11]. Therefore, to realize the benefits of peer support, it is necessary to improve availability of, and satisfaction with, peer support services [4,12].

To improve the availability, uptake, and sustained use of peer support at our comprehensive cancer centre (the Cedars Cancer Centre of the McGill University Health Centre (MUHC) in Montreal, Canada), we are exploring the option of a one-on-one peer support service (known as *OpalBuddy*) facilitated by an open-source patient portal known as *Opal* that our team previously developed and implemented [13]. Used by almost 7,000 patients (mainly cancer patients) at the MUHC, *Opal*'s patient-facing component is a smartphone app through which patients can view their personal health data, access waiting room management services, and view patient education materials tailored to their personal medical contexts (Figure 1). Patients consistently report a need for more personalized information and interactive options within patient portals [14–17], and facilitating digital peer support through the *Opal* app offers many potential advantages over in-person support, such as wider reach, more accessibility, constant availability, more frequent and flexible participation, lower cost, and a certain degree of anonymity, which can improve personal exchanges on sensitive topics [5]. There is some evidence that one-on-one peer support is more effective than group support [6], but effectiveness depends on a good *match* between patient and mentor [18], as a (perceived) mismatch will result in drop out [10,11]. Current peer mentoring programs rely on a coordinator to match patients manually, primarily using type of diagnosis, and a multitude of secondary matching criteria, such as type of treatment, gender, age, family relationships, life experiences, preferred communication format, and interpersonal communication style [10,19–23]. Because patients have different kinds of support needs, they vary in what they consider “a good match” [24], with matching preferences including a similar medical experience (e.g. undergoing the same treatment), a similar life situation (e.g. being a young adult), or the use of a specific communication format (e.g. phone calls). Such “preference-based matching” according to the diverse preferences of individual patients [20,21] is difficult to achieve manually. To enable complex peer matching, *OpalBuddy* proposes to employ an artificial intelligence (AI) matching algorithm using patient-provided information entered into the *Opal* app coupled with data-rich electronic medical records (accessed by the AI algorithm following appropriate patient consent). To develop the AI matching algorithm, we must identify a suitable range of matching criteria for which individual patients may prioritize their matching preferences. To inform this and other design features of the *OpalBuddy* service, we employed a participatory stakeholder co-design approach as used in creating *Opal* in the first place [13].



Please select the number that best describes your health during the last 24 hours.

Radiotherapy is the use of high-energy x-rays to treat cancer.

Our body is made up of many types of cells. Each cell works in its own way to keep us healthy. Cancer forms when a group of cells start to grow out of control.

Figure 1. Screenshots of the patient-facing smartphone app of the Opal patient portal. The OpalBuddy menu item is included as a mock-up and has not yet been implemented. All other menu items and features shown are operational.

Co-design and user involvement in the development process has been shown to improve the quality, utility, and success of mHealth technologies [25,26]. In the present context, "stakeholder co-design" means that patients work in partnership with the clinical and informatics teams to ensure that person-centeredness, clinician acceptability, and DevSecOps (development, security and operations) feasibility are included in the *OpalBuddy* design [13]. As such, patients use their personal experience to help identify needs, preferences, and concerns that inform the technological development [27]. This article reports specifically on how stakeholder co-design was used in the identification of patient preferences to inform design features of the *OpalBuddy* peer support service.

Methods

To gain patient perspectives on the design of a one-on-one digital peer support service, we conducted semi-structured audio-recorded interviews with current Opal users. The COREQ guidelines served to ensure the rigor of this report [28], see Appendix A. Cancer patients were recruited from among the users of the Opal patient portal at the MUHC using purposive sampling to ensure diverse types of cancer. Inclusion criteria included age ≥ 18 years and clinical diagnosis of cancer. Twenty-three users (19 women, 3 men, and 1 unknown gender) responded to an announcement about the study in the Opal app, receiving an email and phone call with more information, after which 21 users were invited to sign a consent form, which 8 women did, 2 declined and 11 had no response. Eight women (four diagnosed with breast cancer, one with myelofibrosis, one with rectal cancer, one with non-small cell lung cancer, and one with an undisclosed type of cancer) completed semi-structured, one-on-one audio-recorded interviews via the Zoom video conferencing service with AW, a female undergraduate student in psychology, trained as a research assistant and supervised by AML and JK.

The interview guide (Appendix B) was developed by the research team, including two patient partners (SJ and TW), and revised after three mock training interviews. Interviews had a median duration of 38 minutes (ranging from 21 to 45 minutes). At the start of each interview, participants were informed about the study's purpose and interviewer's role and asked open-ended questions about their cancer peer support experiences, preferences and concerns. All interviews (6 English; 2 French), were initially transcribed verbatim into original English (AW, DEA, AML) or French (DEA, LG). French transcripts were translated to English (DEA, LG) and all were verified by bilingual members of the research team (AML, LG).

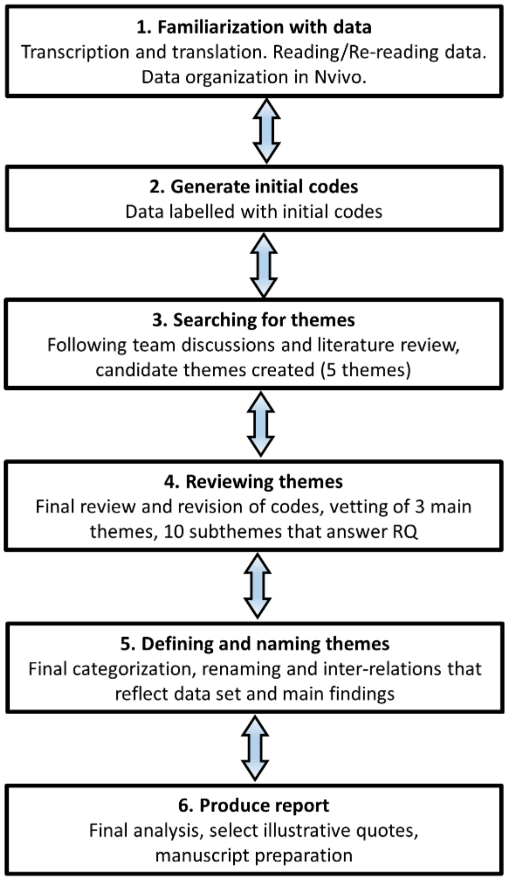


Figure 2. Overview of the thematic analysis procedure that was used to analyze the semi-structured interviews in the OpalBuddy study, adapted from [22,29].

Following a Thematic Analysis approach [29,30], data analysis was carried out in six iterative and intersecting stages conducting content analysis using both deductive and inductive coding to identify themes, subthemes and their inter-relations (Figure 2 presents stages linearly for clarity). Analytical insights developed during data collection and analysis were discussed with all members of the research team at weekly meetings. Data were initially organized and managed in Excel (Microsoft Corporation, Seattle, USA) and subsequently into qualitative data analysis software NVivo (Lumivero, Denver, USA), version Release 1.7.1.

After reading the de-identified interview transcripts several times, XJD and AML generated an initial set of codes using open coding. No additional interviews were added since information redundancy had been reached, with a limitation that the study did not recruit men because of time constraints given resource availability. After team discussion and reflection based on literature, initial codes were re-organized into five candidate themes to accurately reflect the overall data set. Team consensus was sought on creating, defining and re-naming the final three themes and ten subthemes, which achieved the research objectives while accurately capturing the range and depth of responses and their interconnections. In the final analysis and presentation of results, LK, JK and AML conducted verification within and across interviews, identified negative instances [31], and created data tables with vivid quotes to illustrate all subthemes, indicating each respondent's (dis)agreement with a (sub)theme by color-coding in green (agreement), red (disagreement), yellow (mixed response, 'it depends'), or white (did not mention) (Tables 1-4 and Appendix C).

To minimize the risk of being recognized, only audio-recording of the interviews was done (no video); no names were used once the interview was started; and each recording received a unique numeric identifier. The study lead (AML) assigned a new file name and study ID to the transcription after each transcription had been verified against the recording. The final deidentified transcript files were then sent to the research team members who were responsible for the thematic analysis.

The study protocol complied with the Declaration of Helsinki and was approved by the Research Ethics Board of the McGill University Health Centre (Project # 2021-7592). All participants provided written informed consent before the interviews.

Results

Three main themes were identified from the interviews. These are illustrated in Figure 3. Under theme 1, respondents expressed that their *ideal peer mentor can provide support on multiple levels*, distinguishing four sub-themes that describe the type of support that may find helpful: (A) sharing illness experiences, (B) practical informational support, (C) emotional support, and (D) social management coaching. Under theme 2, respondents identified that the *ideal peer mentor has similar lived experience. Three sub-themes related to lived experience were identified*: (A) a similar clinical situation; (B) similar socio-demographics; and (C) there is an interpersonal affinity between mentor and mentee. Under theme 3, respondents outlined how the *ideal mentor will be supported in their role*. In this context, respondents' thoughts on mentor support can be grouped into three sub-themes: (A) formal training [of mentors] may not be necessary, but effective and sustainable peer support requires that mentors receive (B) general guidance and (C) supportive supervision. These themes and sub-themes are described in more detail in the sub-sections below with additional supporting data provided in the tables.

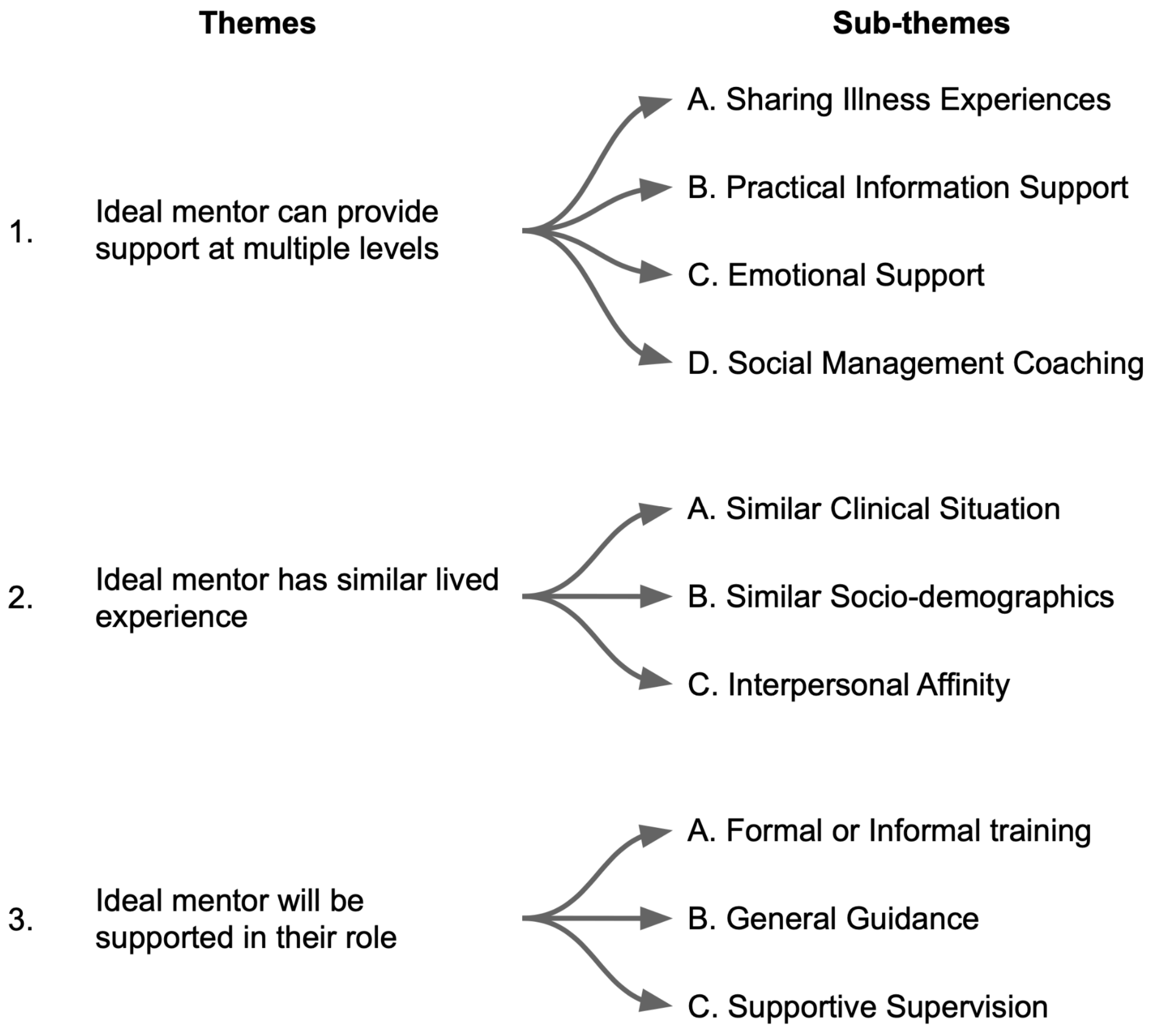


Figure 3. Themes and sub-themes identified from the interviews.

3.1 Theme 1: The ideal mentor can provide support at multiple levels

Respondents expressed a clear need for peer support, explaining its distinctness from social support provided by non-patients: “even if you have tremendous family support and friends, it's never the same as someone who's lived what you’ve lived.” (R8). Respondents’ prior experiences with various peer support formats were mostly positive, but some respondents preferred one-on-one peer support over group support, having found exposure to other patients' negative disease experiences unhelpful or frightening (R3, R4).

Respondents described four types of support they had received from peers that non-peers would not be able to give (Table 1). First, by virtue of (A) **Sharing Illness Experiences**, a new patient feels more prepared for what their experience might look like, giving them "an overall perspective of what [to] expect" (R3). Sharing can also reduce anxiety by normalizing experiences, that is, checking if certain events are normal or require medical attention (R6). Second, peers can use their illness experience to provide (B) **Practical Information Support**. While not a substitute for professional medical advice, peers can discuss how they managed the side effects of chemotherapy, or how to navigate the healthcare system, or provide information on non-medical issues such as insurance or buying wigs. Third, peers can provide multiple types of (C) **Emotional Support** distinct from support provided by loved ones. Peers make patients feel less alone in their cancer journey and are particularly well suited to keeping up morale by encouraging a positive attitude. Optimism from peers is much better received than when family or friends say things such as "you will be fine, you will beat this". This can feel like a "forced cheerfulness" that is unrealistic or belittling (R2, R3, R5, R6): "what the f*** do you know, there's no way you can relate except if you have come through the same thing" (R3). Finally, peers can provide emotional support by encouraging patients to "vent" their fear or anger (R5), which patients may be reluctant to do with family or friends for fear of upsetting them (R6). Fourth, peers can provide what R1 called (D) **Social Management Coaching** to help navigate tense relationships with family and friends, such as how to explain to others you have cancer, or how to handle people's (unhelpful) reactions (R1, R5, R6, R8).

Table 1. Theme 1: Ideal mentor can provide support at multiple levels.

<table>
<tr><th></th><th colspan="8">Respondents</th></tr>
<tr><th>Theme 1: Ideal mentor can provide support at multiple levels</th><th>R1</th><th>R2</th><th>R3</th><th>R4</th><th>R5</th><th>R6</th><th>R7</th><th>R8</th></tr>
<tr><td>A. Sharing Illness Experiences</td><td>🟩</td><td>🟩</td><td>🟩</td><td>🟩</td><td>🟩</td><td>🟩</td><td></td><td>🟩</td></tr>
<tr><td><i>Prepare</i></td><td colspan="8">“the perfect buddy would be somebody who has walked your path, probably 3 to 6 months before you. Who could tell you what's coming up, just to kind of be prepared.” (R4)</td></tr>
<tr><td><i>Normalize</i></td><td colspan="8">“Is this normal for your hair to be like this? Or: How come I've got all these rashes and you don't? It's just comparing notes sort of thing.” (R6)</td></tr>
<tr><td>B. Practical Information Support</td><td>🟩</td><td>🟩</td><td>🟩</td><td>🟩</td><td>🟩</td><td>🟩</td><td></td><td>🟩</td></tr>
<tr><td><i>Medical issues</i></td><td colspan="8">“I'm going to be put on this drug that's very strong, and so I would like support knowing how to handle the drug. What to expect?” (R6)</td></tr>
<tr><td><i>Non-medical information</i></td><td colspan="8">“It can be fun little tips, no big deal. Like, where did you buy your scarves?” (R5)</td></tr>
<tr><td>C. Emotional Support</td><td>🟩</td><td>🟩</td><td>🟩</td><td>🟩</td><td>🟩</td><td>🟩</td><td>🟩</td><td>🟩</td></tr>
<tr><td><i>Not feeling alone</i></td><td colspan="8">“It’s just knowing that you're not alone, really. Because you feel all alone when you're told that you have incurable cancer. Even if you have your family and everything else.” (R8)</td></tr>
<tr><td><i>Encouraging Positive Attitude</i></td><td colspan="8">“Telling you that you're going to get through it, putting positivity into the mind and morale of the person who has cancer.” (R7)</td></tr>
<tr><td><i>Venting</i></td><td colspan="8">“Often, you don't need answers or advice. Sometimes, you just need to vent to someone who has been there.” (R5)</td></tr>
<tr><td>D. Social Management Coaching</td><td>🟩</td><td></td><td></td><td></td><td>🟩</td><td>🟩</td><td></td><td>🟩</td></tr>
<tr><td><i>Managing social relations</i></td><td colspan="8">“emotional support in management with people around you. How to explain what you're going through to people” (R1)
“when we tried to explain it to people, like my family [I have incurable cancer], a lot of them [said] ‘you'll beat this and you'll be okay’ and all the rest of it. And you don't know how to answer it. [I needed help] how to handle people and their reactions to my type of cancer.” (R6)</td></tr>
</table>

Green: respondent has support need. Clear/white: does not mention.

3.2 Theme 2: The ideal mentor has similar lived experience

The second theme explores characteristics of an ideal mentor, resulting in three criteria that can be used for peer matching: A) Similar clinical situation. B) Similar socio-demographics. C) An interpersonal affinity. Each is discussed below, and illustrated in Tables 2, 3 and 4, and in Appendix C.

A. Similar clinical situation: someone else going through the cancer adventure

> *"It's the cancer, lung cancer in my case, and experience that counts, the disease itself." (R8)*

With one exception (R7), all respondents wanted a peer mentor in a similar clinical situation, expecting an appropriate clinical match to provide better practical and emotional support. For some, any cancer diagnosis was enough, but others expected a mentor to have at least the same type (lung, breast, liver) and ideally subtype of cancer (hormonal vs triple negative, same mutation(s)). Receiving the same treatment can not only make practical advice more relevant, sharing the same diagnosis can make a patient with a rare cancer feel less alone (R4). Clinical similarity also implies sharing a similar prognosis, which can not only help tailor practical information needs, but can also reduce emotional distress. Patients with favorable prognosis can feel frightened seeing peers who are worse off, while patients with terminal cancer can feel hopeless meeting patients with curable cancer, feeling "I'm the only one that [is] never going to get over it" (R6). Finally, the ideal mentor is someone who is "three steps ahead of you" on the cancer journey, "giv[ing] you an idea of what's coming up for you around the corner." (R4). A mentor who is too far ahead in the cancer care pathway can be both irrelevant (R3) and emotionally challenging, such as for a respondent with terminal cancer. She preferred to be matched with a peer with terminal cancer, but “not too terminal” because being confronted with “the final stage” would be too difficult (R6). Finally, an illness experience that took place several years ago can make a peer’s practical information outdated, as “hopefully, there will be new research and there will be new tests” (R4).

Table 2. Theme 2: Ideal mentor has similar lived experience–sub-theme A: similar clinical situation.

	Respondents							
Theme 2: Ideal mentor has similar lived experience	**R1**	**R2**	**R3**	**R4**	**R5**	**R6**	**R7**	**R8**
Sub-theme A: Similar clinical situation (“*Someone else going through the cancer adventure”)*	🟩	🟩	🟩	🟩	🟩	🟩	🟥	🟩
Disagree	“even if I hadn't had cancer, I could have helped someone with cancer” (R7)							
Agree	“we all went through the same experience - every experience is different - but we all went through the same trauma, I would say, of living through cancer” (R2)							
Diagnosis (sub/type of cancer)	“It's the cancer, lung cancer in my case, and experience that counts, the disease itself.” (R8)							
Prognosis (curable/terminal)	“mine is a terminal cancer [..] I don't want to be matched up with anybody who has [a curable cancer], because that's not going to happen to me. And it will make you kind of feel like: ‘woe is me.’” (R6)							
Timing of care pathway	“are you currently in treatment, or have you finished your treatments? Temporality” (R5)							

Green: prefers a clinical match. Red: matching on clinical criteria unnecessary.

B. Similar socio-demographics: someone like me

> *“If it was, let's say an 80-year-old man? I would not necessarily reach out to them. But if it was like someone like me, I would find that useful” (R1)*

Having “a similar illness experience” goes beyond clinical criteria, referring also to the way the cancer experience affects, or is affected by, someone’s life situation, which can differ depending on socio-demographics such as gender, age, family situation or employment status (see Table 3 for summary, and Appendix C for illustrative quotes). For some, including respondents with unfavorable prognosis (R6, R8), socio-demographics were unimportant: “When you have this disease, everything else falls out the window. I can tell you that much. All your experiences, your prior work, your family status, it doesn't matter.” (R8). Yet, even for them, gender mattered because it facilitates emotional connection (“as a woman it's easier for me to talk to another woman” (R2) and makes practical advice more relevant: “I don’t want to be sexist, but guys they don’t have to worry about running the household and keeping things going, so matching female to female because they’re going through the same problems” (R6).

Several respondents found age an important socio-demographic consideration, especially two younger respondents who don’t recognize themselves in older patients (R5) and feel isolated as “older patients are not interested in talking to someone like me” (R1). However, age was relevant for various indirect reasons, assuming age reflects similarity in family status (R4, R5), employment status (R3) or menopausal status (R4). In other words, what is important is not age itself, but “where you are in your life” (R5). Age is a crude proxy to capture similarities in ‘life stage’: someone who is 25 may live with their parents and go to college or be married with children and have a fulltime job. Similarities in ‘life stage’ are better captured by other socio-demographics such as family situation and employment status.

Other than gender and ‘life stage’, other socio-demographic considerations (language, geographic location, shared interests) were generally seen as unnecessary. Exceptions included patients who indicated specific support needs related to language barriers (R3, R5), or a preference to meet in person (R3, R8).

Table 3. Theme 2: Ideal mentor has similar lived experience–sub-theme B: similar socio-demographics. See Appendix C for illustrative quotes.

	Respondents							
Theme 2: Ideal mentor has similar lived experience	**R1**	**R2**	**R3**	**R4**	**R5**	**R6**	**R7**	**R8**
Sub-theme B: Similar socio-demographics (*"Someone like me"*)								
General	🟩	🟥	🟩	🟩	🟩	🟥		🟥
Gender	🟩	🟩	🟩	🟩	🟩	🟩		🟥
Age (life stage)	🟩	🟥	🟩	🟩	🟩	🟥		🟥
Family situation		🟥	🟩	🟨	🟩			🟥
Employment status		🟥	🟩	🟨	🟩	🟥		🟥
Language			🟩		🟩			
Geographic location			🟩					🟩
General interests			🟥					

Green: prefers match on socio-demographic factor. Red: matching on that socio-demographic factor unnecessary. Yellow: mixed response ("It depends"). Clear/white: does not mention.

C. Interpersonal Affinity: it has to jive

> "It all depends how well you gel with who you're matched up with" (R4)

The final important lived experience sub-theme is interpersonal affinity, also described as "hitting it off." Respondents assumed such a "click" can only be assessed through direct personal interaction and cannot be (algorithmically) pre-determined. Yet, respondents articulated quite clearly what interpersonal communication style they prefer from their mentor (see Table 4). Some (R2, R5) want a "good listener" who encourages patients to express their emotions, without enforcing optimism or rushing into practical solutions:

> *Good listening is not always being optimistic. Someone who always tells me 'It's going to be okay, it's going to be okay'. Look, can I have the right to be angry? […] Stop looking for a solution, I have the right to vent and say that it bothers me. That is good listening. (R5)*

Others (R3, R4) expect quite the opposite approach from their mentor: not dwelling on negative emotions but providing practical solutions so patients can "focus on the positive and get on with life" (R3, R4). While some respondents appreciate both approaches (R6, R7), others clearly preferred one style, suggesting they will feel unsupported by a mentor with a different approach. Patients looking for emotional support by "express[ing] the negativity of the experience" (i.e. venting) will find a solution-focused mentor to be dismissive of their pain and suffering (R2, R5). While patients seeking practical information will see sharing of negative emotions as communicating "in a negative, depressive way that actually doesn't help" (R3, R4).

Table 4. Theme 2: Ideal mentor has similar lived experience–sub-theme C: interpersonal affinity.

	Respondents							
Theme 2: Ideal mentor has similar lived experience	**R1**	**R2**	**R3**	**R4**	**R5**	**R6**	**R7**	**R8**
Sub-theme C: Interpersonal Affinity								
"It has to jive"	"It all depends how well you gel with who you're matched up with" (R4) "sometimes, you just don't feel the connections. […] Even though it's technically the best match" (R8)							
Good listener (sharing negative emotions)		🟩	🟥	🟥	🟩	🟩	🟩	🟩
	"I would like this person to be able to listen, first of all, and not to push me into specific solutions." (R2) "[some] people need to talk out their pains and sufferings" (R4) "a lot of empathy, a lot of listening. Listening to what they have to say and then being like 'I've been through this before'" (R7)							
Solution-focused	🟩	🟥	🟩	🟩	🟥	🟩	🟩	

(positive attitude)	“talk about what they did to help them get over it quicker.” (R4) “Telling you that you're going to get through it, putting positivity into the mind and morale of the person who has cancer.” (R7)

Green: likes this communication style. Red: dislikes this communication style. Clear/white: does not mention.

3.3 Theme 3: The ideal mentor will be supported in their role

Our respondents made various suggestions to improve the sustainability and effectiveness of peer support, suggesting an AI-powered algorithmic peer matching service should be embedded in a peer support program that provides (A) **Formal or Informal Training**, (B) **General Guidance**, and (C) S**upportive Supervision** of its peer volunteers.

Respondents thought being a mentor is challenging, and being well-intentioned is no guarantee that peer support will actually be helpful (R3, R5). Respondents suggested communication training might be helpful to mentors (R2, R3, R5, R6, R7), but also questioned if good mentoring skills such as storytelling and empathy can be learned in basic training (R4, R5, R6, R7). Interestingly, R8 suggested formal training may even worsen peer support by limiting spontaneity and authenticity. Rather, only mentors with suitable skills should enroll in the program, to be reinforced by giving new recruits “guidance” (R6) and “general rules” (R8) that explain roles and responsibilities expected of mentors and mentees.

Importantly, the rules must clarify the limits of peer support: “It needs to be very clear that we are cancer patients who have been through it. We are not psychologists. We are not social workers. We are not therapists.” (R4). Peers can share their personal experiences and help others with their decision-making processes, but they should not give medical advice, nor recommend, promote or sell specific treatments, services or products (R3, R2, R8). While online peer support groups often rely on moderators to redirect medical issues to professionals (R5), in one-on-one peer exchanges such external monitoring would violate privacy and confidentiality. Instead, participants can be regularly reminded of the general rule: “If you have medical questions, don't ask your Buddy, go see your nurse.” (R5). Thus, clarifying the limits of peer support serves to protect patients from unreliable medical advice, making sure peer support does not “divert away from professionals” (R5). Knowing the limits of peer support can also help protect the emotional well-being of peer mentors, helping them to recognize “an emotional load that's too heavy” to carry (R5), such as a mental health crisis or the death of a patient, and reach out for emotional support from a supervisor or “volunteer leader” (R5, R6). Mentors also need practical support, like a list of practical, local services and resources such as information on unemployment insurance or where to buy wigs. Finally, respondents suggested having additional mentors available and assuring reliable funding are important to ensure continuity of a peer support service.

Discussion and Conclusion

We now situate our respondents’ perspectives within previous research and highlight how our findings help optimize the design of the OpalBuddy peer support service. Our work has shown that an ideal peer mentor can provide support at multiple levels, that they have similar lived experience to the patient they are supporting, and that there is an expectation that peer mentors will be supported in their role by the professional healthcare organization where the peer support service is offered. First, our results confirm previous work that patients seek and receive both practical information and emotional support from peers [3,4,32], while adding that peers help with ‘social management’ of family and friends [33]. Our findings highlight that different support needs are not always complementary and can result in conflict. Patients seeking practical support can feel unsupported when grouped together with patients who want to talk through negative emotions [18,32]. Being exposed to the suffering of others is a well-documented barrier to group peer support [3,9,11,34], while this exposure is reduced in a one-on-one setting [23]. By clarifying role expectations at enrolment, AI-facilitated support can potentially better match patients with mentors, and mentors can further clarify and personalize the kind of practical or emotional support they are able to provide. By providing feedback on the alignment of support needed and received, (re)matches can be improved [18,24]; thereby strengthening future AI-facilitated matches.

Second, our respondents agreed that a similar clinical situation and matching gender were important for a good match. Other socio-demographic factors (age, family, and employment status) were generally considered less essential, except for patients seeking support on a specific issue related to such a factor, such as young adults seeking support from people in a similar life stage [35,36], or patients needing support for specific family issues. Similar age is a crude proxy for similar life events. More accurately, we can identify patients' specific support needs related to their life stage and match them with a mentor with relevant socio-demographic factors such as family status or employment status.

These clinical and socio-demographic criteria (as listed in tables 2 and 3) largely align with existing matching practices that have been reported in the literature [10,19,20]. Our findings add an important new criterion: feeling a personal connection with a peer mentor (see also [18]). Measuring or predicting interpersonal affinity is a challenge. Hartzler and colleagues found that a formal tool to measure personal language style was "confusing and overwhelming", for patients [21]. A peer matching algorithm is unlikely to be equipped to measure whether peers will have a good interpersonal relationship , nor can it do a psychological analysis to assess compatible personalities. Instead, our findings suggest that interpersonal affinity can be improved if we better match patients' specific peer support needs with a mentor with a suitable communication style. That is, using a questionnaire at enrolment, we can identify patients who need to 'vent' and match them with a mentor who self-identifies as a good listener, while patients who prioritize informational support are connected to a solution-focused mentor. In an algorithmic context, feedback from mentees about (mis)matches can be used to improve future matchings [24].

Third, like Hoey and colleagues [37], our findings question the need for formal training as participants doubt the interpersonal skills needed can be taught in short, formalized training. Randomized controlled trials (RCTs) have been unable to show that training improves the quality of peer support [6,38]. Long-term experience in peer support may be more important than training [5,39], and a supportive supervisor who gives tailored advice may be more impactful than generalized training [37].

Fourth, continuity is a major challenge for peer support [3,20]. To improve continuity, OpalBuddy can offer several peer mentor profiles to choose from, facilitating a re-match if a mentor is mismatched or becomes unavailable. Even if never contacted, simply knowing there are several "others like me" improves emotional well-being [20]. It will require a larger mentor pool, and careful consideration of which personal (health) details to include in a mentor profile visible to many patients. Finally, we do not recommend "firing" (R4) long-time volunteers. While their treatment experiences may become outdated, peer mentors with "many years of experience" are crucial to the quality of support programs [5]. They can be matched with patients who primarily seek emotional support from a mentor rather than practical informational support or offered “alternative ways to be involved” such as recruiters, trainers or supervisors of peer mentors [20].

The main limitation of this study is the lack of representation of all cancer patients. This study included only eight women, and the findings may have been different had men been included. Although our study was announced to all cancer patients who use the Opal patient portal (which has a roughly 0.55:0.45 split of female to male users), only 23 patients responded to the announcement, of which only three were men, and only the eight women who participated ultimately signed the consent form. Due to time constraints for completing the interviews, it was not possible to pursue an additional announcement of the study. Future work should examine patient preferences among men before implementation of an AI-powered peer support matching algorithm that caters to both women and men.

In conclusion, a peer support service in a patient portal is a promising digital health intervention that can provide a variety of emotional and practical benefits to cancer patients. The design of the peer support service in the Opal patient portal app – and the program it will be embedded in – must be informed by the following patient preferences. First, the app should use a questionnaire to identify relevant ‘life stage’ criteria (i.e. age, family situation, employment status) and type of support needed (practical or emotional, specific topics). Combined with clinical criteria, these will allow matching with a mentor who has similar characteristics and a suitable communication style. Second, before participation, peers should be provided with basic rules to follow, so that patients and mentors are clear on role expectations of peer support. Third, providing peers with the ability to provide feedback on the match (in case of unavailability or mismatch) allows the potential for future algorithmic matches to be better tuned to the specific needs of mentees.

Relying on these patient preferences, a digital one-on-one peer support service promises to improve the availability and effectiveness of peer support for cancer patients, by improving the quality of the match between patient and mentor. The next step is to use these patient preferences to inform the design of a pilot OpalBuddy service in the Opal app. The pilot service will be tested by a larger and more diverse (in terms of sex and gender, age range, diagnoses, stage of disease, etc) patient population who will provide feedback in a survey and focus groups, as continuous user involvement will assure the utility, quality, and patient-centeredness of the service's final design [13].

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Author contribution

Conception and design: A.M.L., L.G., S.J., J.K.; Interview guide: A.M.L., K.A., L.G., S.J., R.M., T.W., J.K.; A.W. conducted the semi-structured interviews. Analysis and interpretation: L.K., A.M.L., X.J.D., D.E.A., J.M., B.W., J.K.; Translation from French to English: D.E.A., L.G.; Verified translations: A.M.L., L.G.; Patient partners: S.J. and T.W. Ethics and study coordination:

A.M.L., L.G., J.K.; L.K. wrote the main manuscript text. All authors reviewed and approved the final version of the manuscript and agreed to hold responsibility for the work's accuracy and integrity.

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Data availability

The research data are not shared.

Declarations

Competing interests

The authors declare no competing interests.

Ethical approval

The study protocol complied with the Declaration of Helsinki and was approved by the Research Ethics Board of the McGill University Health Centre (Project # 2021-7592). All participants provided written informed consent before the interviews.

Consent to participate

Informed consent was obtained from all participants included in the study.

Consent for publication

The participants were informed that the results of this study may be published in an article in a journal.

Conflict of interest

The authors declare no competing interests

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