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Abstract:	<p>BACKGROUND: Significant intervals from the identification of suspicious symptoms to a definitive diagnosis of cancer are common. Streamlining pathways to diagnosis may increase survival, quality of life post-treatment, and patient experience. Discussions of pathways to diagnosis from the perspective of patients and family members are crucial to advancing cancer diagnosis.</p> <p>AIM: To examine the perspectives of a group of patients with cancer and family members in Alberta, Canada, on factors associated with timelines to diagnosis and overall experience.</p> <p>METHODS: A qualitative approach was used. In-depth, semi-structured interviews with patients with cancer (n=18) and patient relatives (n=5) were conducted and subjected to a thematic analysis.</p> <p>FINDINGS: Participants struggled emotionally. Relevant to their experience were: potentially avoidable delays, concerns about health status, and misunderstood investigation process. Participants emphasized the importance of their active involvement in the care process, and had unmet supportive care needs.</p> <p>CONCLUSION: Psychosocial supports available to potential cancer patients and their families are minimal and crucial for improved experiences before diagnosis. Access to other patients' lived experiences with the diagnostic process and with cancer, and an enhanced supportive role of family doctors might improve outcomes for patients and families.</p>
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3 From symptom to cancer diagnosis: Perspectives of patients and family members in Alberta, Canada

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Perspectives about the cancer diagnosis period

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24

25 Abstract

26 BACKGROUND: Significant intervals from the identification of suspicious symptoms to a definitive
27 diagnosis of cancer are common. Streamlining pathways to diagnosis may increase survival, quality of
28 life post-treatment, and patient experience. Discussions of pathways to diagnosis from the perspective
29 of patients and family members are crucial to advancing cancer diagnosis.

30 AIM: To examine the perspectives of a group of patients with cancer and family members in Alberta,
31 Canada, on factors associated with timelines to diagnosis and overall experience.

32 METHODS: A qualitative approach was used. In-depth, semi-structured interviews with patients with
33 cancer (n=18) and patient relatives (n=5) were conducted and subjected to a thematic analysis.

34 FINDINGS: Participants struggled emotionally. Relevant to their experience were: potentially avoidable
35 delays, concerns about health status, and misunderstood investigation process. Participants emphasized
36 the importance of their active involvement in the care process, and had unmet supportive care needs.


37 CONCLUSION: Psychosocial supports available to potential cancer patients and their families are minimal
38 and crucial for improved experiences before diagnosis. Access to other patients' lived experiences with
39 the diagnostic process and with cancer, and an enhanced supportive role of family doctors might
40 improve outcomes for patients and families.

41

42 Introduction

43 Cancer is the leading cause of death in Canada [1]. About half of Canadians will develop cancer in their
44 lifetime, and about one-fourth will die of the disease [2]. Evidence suggests that diagnosing cancer at
45 earlier stages may be associated with improvements in survival [3].

46

47 Significant intervals from first noticing a symptom to receiving a cancer diagnosis (known as the  48 diagnostic period) have been widely documented in the literature [4, 5], and related to later stages at 49 diagnosis, as well as suboptimal survival, quality of life post-treatment and patient experience [3, 6]. In 50 Alberta, analyses of administrative data spanning 2004-2011 described potentially preventable long 51 periods from suspicion to diagnosis for breast, colorectal, and lung cancers [7-10]. In Canada and across 52 the world there are substantial variations in the length of the diagnostic period for different cancers [4, 53 11], and numerous studies have focused on understanding factors that may influence this timeline in 54 order to improve health outcomes and patient experience [12].


55
56 The importance of discussing the path to diagnosis from the perspective of patients and family members 57 is increasingly acknowledged in the literature [13]. Receiving a cancer diagnosis is often preceded by a 58 period of waiting for a diagnosis following the discovery of symptoms, which is anxiety-provoking [14]. 59 The psychosocial impacts of the wait may be accentuated if patients believe there have been 60 inefficiencies in their pathway to diagnosis. In Canada, discussions to advance cancer diagnosis are 61 mostly based on timeline-related information available in administrative databases [9, 10], and not so 62 much on perceived timelines and patient and family experiences [6, 15]. This study was designed to 63 contribute to filling that gap. The objective was to examine the perspectives of a group of patients and 64 family members in Alberta, Canada, on factors associated with timelines to diagnosis and overall patient 65 and family experience. Learning more about perceptions and experiences in the diagnostic period may 66 help inform the development of interventions to minimize stress and improve satisfaction with care, 67 which may have a significant impact on wellbeing [16].

68

69 Methods

70 Participants

71 Participants were associated with the Patient & Family Advisor Network (PFAN) of CancerControl Alberta
72 (Alberta Health Services). PFAN is a community of people who are committed to using their experiences
73 to help improve the health system. Participants in this study were patients with cancer or relatives of
74 patients with cancer who had received a cancer diagnosis within the last three years, and were living in
75 Alberta at the time of diagnosis.

76
77 To recruit participants, the PFAN coordinator sent all PFAN members an electronic engagement request
78 inviting expressions of interest in participating in the study. The PFAN coordinator then sent interested
79 members an email with information about the study and a screening questionnaire for them to
80 complete. Responses from the questionnaire were used to purposefully select participants with 

81 different types of cancer, within different sex and age ranges, assigned to curative or non-curative
82 treatment, and residing across Alberta (rural and urban) to ensure a variety of cancer experiences [17].

83 The PFAN coordinator invited selected participants to be part of the study and sent them an email that
84 included a consent form to be reviewed prior to the interview. Additional participants were invited to
85 participate in the study until data saturation was reached [17]. In total, 20 interviews were conducted;
86 with the participation of 18 patients and five family members.

87 Procedure

88 The framework used for the study was 'Model of Pathways to Treatment' [18-20]. It identifies four
89 intervals from suspicion of a health problem to receiving treatment: 1) from detection of symptoms to
90 perceiving a reason to discuss symptoms with a healthcare provider (*appraisal*); 2) from perceiving a
91 reason to discuss symptoms with a healthcare provider to first consultation (*help-seeking*); 3) from first

92 consultation to formal diagnosis, including the initiation of investigation, prescription of tests,
93 examinations, and diagnosis (*diagnosis*); and, 4) from formal diagnosis to start of treatment (*pre-*
94 *treatment*) [19]. The study covers the first three intervals, referred to collectively as the diagnostic
95 period.

96
97 The study used a qualitative research approach [17, 21]. This method was selected to facilitate
98 exploration of perspectives and experiences to capture new insights that may inform how to improve
99 experiences during cancer diagnosis, complementing the previous quantitative approaches undertaken
100 in Alberta. In-depth, semi-structured interviews were used for data collection. Interviews followed an
101 interview guide that was developed in close collaboration with PFAN leadership and with feedback from
102 patient advisors affiliated with the Cancer Strategic Clinical Network (S1 and S2 Appendices). Using
103 accepted qualitative research standards [22], pilot interviews were conducted with four patients with
104 cancer to ensure the interview guide answered the proposed research objective. The interview guide
105 covered topics such as how participants made sense of their symptoms, why they chose to visit a
106 healthcare provider and how they experienced going through appointments, referrals, and tests before
107 they were provided with a definitive cancer diagnosis. It also included a section on recommendations for
108 improvement including the need for emotional support during the diagnostic period.

109
110 The study was conducted with written ethics approval granted by the Health Research Ethics Board of
111 Alberta –Cancer Committee (Study ID: HREBA.CC-18-0210). Interviews were conducted by APB, a
112 qualitative researcher by background, with a PhD in social sciences, with interest in the diagnostic
113 period and no previous work in the area with patients or family relatives. She was involved in the early
114 development of the study, and had no prior relationship or sharing of personal information with the
115 participants approached for interview. Interviews were conducted face-to-face at a time and location

116 convenient for each participant. Most participants were interviewed in a room at their closest cancer
117 centre, and three in a meeting room in the facility where the PFAN coordinator worked. In one case it
118 was not possible to find a convenient location and the interview was conducted through
119 videoconference. There was no presence of non-participants during the interviews. Before proceeding
120 with each interview, participants were invited to sign the consent form that they had received from the
121 PFAN coordinator by email. Interviews took place between June 26 and September 7, 2018, and lasted
122 an average of 41 minutes (range 29-88 minutes). During each interview the researcher took field notes
123 to maintain contextual details and non-verbal expressions. All interviews were audio-recorded and
124 subsequently transcribed verbatim. To protect the identity of participants, at the transcription stage
125 each interview was assigned an identification number and any identifying information was deleted.

126 **Analysis**



127 Interview transcripts were imported into NVivo Version 11 (QSR International, Australia). Transcripts
128 were thematically analyzed using an inductive data-driven coding process to reflect on how participants
129 made meaning of their experiences without predetermined theories [23]. This process entailed a
130 methodological review of the full text of each interview transcript to detect recurrent themes that were
131 then organized into a set of codes that were systematically applied to fragments of text [21]. The
132 researcher who conducted the interviews did all of the coding. To ensure consistency and
133 trustworthiness [23], a second researcher coded randomly-selected segments of text. The two
134 researchers discussed their interpretation and codes until they reached consensus. To increase validity,
135 participants were sent research findings and given the opportunity to provide feedback (by email or
136 phone), and findings and feedback were validated in a subsequent group discussion with eight patients
137 with cancer [23].

138

139 Results

140 Patients with cancer and family members who participated in the study represented ten different
141 cancers, 74% of them were women (n=17), their median age was 59 years (range 42-76), 70% resided in
142 urban locations (n=16), 65% of patients had been treated with curative intent (n=15), and the median
143 time between the date of diagnosis and the date of the interview was 19 months (range 2-36).

144 Participants had diverse experiences during the diagnostic period, but some commonalities exist.

145 Thematic analysis revealed three salient themes as being relevant to their experience (S3 Fig):

146 potentially avoidable delays, concerns about health status, and misunderstood investigation process.

147 Participants struggled emotionally in the period between identifying symptoms and receiving a cancer
148 diagnosis, and had suboptimal care experiences.

149 **S3 Fig. Emergent themes relevant to cancer patients and family members' experience during the**
150 **diagnostic period**

151 **Potentially avoidable delays**

152 Participants referred to potentially avoidable long periods of time spent in the diagnostic period. They
153 mentioned delays related to the patient, to the doctor, and to the health system.

154

155 Patient-related delays. Initial inaction by patients caused delays. Patients did not initially act because
156 they did not identify symptoms or did not think symptoms were signs of a serious problem. An
157 additional cause of delay was that patients postponed visits with their doctor due to fear of cancer,
158 being busy, feeling embarrassed or not feeling it was an appropriate use of the doctor's time.

159

160 Having some degree of awareness about the seriousness of symptoms, and knowing individuals who had
161 experienced cancer played a very important role in acknowledging the problem and deciding to go to

162 the doctor promptly after noticing a symptom. As this participant explained it: “A friend from the
163 community had [breast cancer] and died of it. So, I felt this lump. As soon as we got home, I made an
164 appointment” [breast cancer patient 10].

165
166 Family doctor-related delays. In some cases, participants reported that they believed that their doctor’s
167 inability to identify symptoms led to patients undergoing investigation for diseases other than cancer, or
168 a later visit to the emergency department. One participant explained this delay in eventually
169 investigating and identifying cancer as: “she just developed this cough. It wouldn’t go away. We took her
170 to the doctor and just said it’s allergies [...]. Several months went by, and she wasn’t any better. We
171 went to the doctor again and again before even thinking of cancer” [relative of lung and brain cancer
172 patient 12].

173
174 Participants perceived family doctors as the patients’ doorway to the diagnostic pathway. In the context
175 of their experience, some participants referred to their family doctor as the person who restricted
176 access to the investigation of cancer symptoms and jeopardized a timely diagnosis. One explained: “I
177 guess it couldn’t be cancer if [the doctor] didn’t even check for it” [breast cancer patient 2], and:

178 “It isn’t until [doctors] are convinced something is wrong, nothing is going to happen [...]. It was
179 not until we did the private MRI that we found out [she had cancer]. That triggered the doctor
180 really believing that something was wrong and doing something about her cancer” [relative of
181 lung cancer patient 3].

182
183 In some cases, participants debated about the role of family doctors and agreed that doctors could play
184 a bigger role at supporting patients in navigating the healthcare system. One participant, reflecting on

185 her experience, said: “I’ve had this family doctor for many years [...]. I felt that he should have been
186 more involved in getting things moving quicker” [colon cancer patient 14].

187
188 System-related delays. Long waiting times to see a specialist, undergo testing or learn test results
189 delayed diagnosis. Some participants spent extensive time following the multiple steps involved in the
190 investigation. They shared frustration with what they reflected to be an uncoordinated and inefficient
191 process. A few shared that there was not much they could have done about it, while others expressed
192 that “there’s a responsibility for [patients] to be more proactive” [ovarian cancer patient 4]. As
193 explained by this participant:

194 “In my case, people doing the test didn’t follow through. So, that process was dropped. But I still
195 had those symptoms, so we should have done more investigation. I had to be assertive enough
196 to say to the doctor: ‘I need this exam’” [colon cancer patient 15].

197
198 Being familiar with cancer and having system connections or being knowledgeable about how the
199 system works were mentioned as enablers for self-advocacy during the diagnostic period and prompt
200 diagnosis. One participant explained, for example:

201 “I was phoning and trying not to harass, but I knew what my options were, what I can do. I
202 remember phoning my family doctor and, you know, ‘can you get us in?’ to get a colonoscopy
203 earlier. Unless you are an advocate, you get lost in the system” [relative of lung cancer patient
204 2].

205 **Concerns about health status**

206 Participants mentioned that it was stressful to consider the possibility of a major health condition such
207 as cancer. In most cases, family members were mentioned as the primary source of emotional support.
208 Some participants also assigned an emotional supporting role to family physicians: “they could be the

209 hub, supporting the patient” [prostate cancer patient 5]. In terms of the timing of health concerns, most
210 participants mentioned that before the investigation “you want to trivialize it, it’s not a big deal” [breast
211 cancer patient 1], but once the investigation process started, they began to consider the possibility of a
212 serious health problem.

213

214 Participants shared three elements that triggered being concerned about a serious health problem. First,
215 the fact that their family doctor decided to pursue testing or referral to a specialist prompted worries. “I
216 thought: ‘nobody was too worried about it until now, why do I have to go [to the specialist] suddenly?’
217 So I became worried” [anal cancer patient 18]. Second, the realization that the investigation was not as
218 straightforward as they thought caused concerns. “It was scary; Dr. [name] sent us for blood tests again,
219 and the scans, that was like two days” [relative of prostate cancer patient 5]. Third, the existence or
220 non-existence of communication with healthcare providers during the investigation caused patients to
221 worry about their health. “I was having the mammogram, the radiologist was there. She showed me
222 what she saw on the screen and she said: ‘this is what I am looking at’, and I’m concerned about that”
223 [breast cancer patient 17]. “A lot of cancer people say that at the radiology place, when they are doing
224 [a mammogram], the radiologist often comes in and explains; they can often tell right away. But
225 nothing, that did not happen, and I’m worried” [breast cancer patient 1].

226 **Misunderstood investigation process**

227 The process of investigation was described differently by participants who accessed care through the
228 emergency department and those who accessed care through their family doctor. Participants who
229 went to the emergency department described the investigation as “very abrupt, instantaneous and with
230 no stress, because it was right away” [breast cancer patient 2]. In several cases, participants who saw
231 their doctor and had the investigation initiated by their doctor explained that the investigation was
232 cumbersome and stressful. They referred to specific complications such as having tests done multiple

233 times or having to travel to inconvenient locations for medical appointments, and also to the fact that it
234 involved multiple steps that were often unexpected and seemed uncoordinated. As explained by this
235 participant: “I just thought I was gonna go in for a mammogram [...]. I went for my mammogram and I
236 thought everything would be fine, but they called me back and they said: ‘we need to see you again’”
237 [breast cancer patient 10]. What seemed particularly stressful for participants was the fact they did not
238 understand what the investigation process entailed, and were unsure about what to expect. As
239 explained by one participant:

240 “There didn’t seem to be a plan, really. I mean, I know they have a plan because that’s what
241 they’ve done a million times before, but they don’t share that too much other than to say: ‘we
242 are going to do a biopsy or whatever test’. There is not a whole lot of explanation [...]. I was just
243 following what they were saying, and I was: ‘ok, I’ll just show up there for that appointment and
244 do that’” [breast cancer patient 16].

245
246 After reflecting on how challenging it had been for them to navigate the investigation process, some
247 participants stressed that others might struggle. In particular, they referred to patients from cultural
248 minorities, elderly, with less education or other characteristics that may impact their ability to advocate
249 for themselves. “Where am I supposed to go? People don’t have a clue; [...] you feel lost, it’s very scary”,
250 and “I kept saying: ‘if you were an immigrant coming in here, how would you ever figure all this out?’”
251 [anal cancer patient 18]. Participants emphasized the importance of having family members who can
252 support patients, and the need to improve the coordination of services and have resources available to
253 patients: “whether it be a nurse navigator, whether it be some written information, or like just
254 somebody to tell you: ‘this is what [the investigation process] looks like and these are the timelines’”
255 [breast cancer patient 6].

256

257 Discussion

258 The study described the diagnostic period from the perspective of a group of patients with cancer and
259 family members in Alberta. Findings contribute to the literature by focusing on perceived challenges
260 along the pathway to diagnosis, and thus may have implications for the development of interventions to
261 improve the experiences of patients and family members. Of relevance, findings showed that patients
262 and family members participating in the study experienced anxiety and had suboptimal experiences.
263 Participants expressed the importance of self-advocacy and wanting to have an active role in their care,
264 and suggested unmet supportive care needs when navigating the system. These findings highlight a
265 need for further discussion on the provision of psychosocial supports to potential cancer patients and
266 their families before they have a confirmed diagnosis of cancer.

267

268 The finding of participants feeling distressed during this period is consistent with previous studies
269 undertaken in various countries including the United States, Denmark and Canada [13, 18]. Before
270 diagnosis, individuals with symptoms suspicious of cancer face uncertainty and threat of a serious illness
271 while having to undergo medical appointments and tests, which might be fearsome, uncomfortable and
272 demanding. Findings from the study are also in alignment with the literature by indicating that fear
273 about having a serious health condition is an important cause of anxiety among patients and family
274 members waiting for diagnosis [24]. Also in accordance with the literature, findings showed that
275 perceived long timelines add stress to an already stressful situation [25]. Consistent with previous
276 research, participants associated delays with their inaction or late action in seeking medical attention
277 [6], with their doctor's failure to correctly identify cancer symptoms [12, 26], and with system
278 inefficiencies including variable access to specialists and testing and limited coordination of care [27,
279 28]. Of relevance, participants in the study referred to cancer awareness and second-hand experience

280 with cancer as two important elements supporting the patient’s prompt consult with a doctor. While the
281 relevance of cancer awareness has been previously acknowledged [29, 30], the influence of shared
282 cancer stories on the experiences of potential cancer patients with the diagnostic period has not been
283 discussed in the literature. In the post-diagnosis literature, access to patients’ real experiences with the
284 disease has been reported important in providing general support to patients with cancer including the
285 provision of information related to cancer and care process, and emotional help [31, 32]. The potential
286 role of the socialization of these experiences in not just helping individuals seek medical attention, but
287 also dealing with information and emotional aspects of a prospective cancer diagnosis at the beginning
288 of their journey requires further investigation.



289
290 A relevant contribution from our study is the importance of self-advocacy and the need to better
291 support patients and family members acquire an active role in their care prior to receiving a cancer
292 diagnosis. Similar to what has been documented in the post-diagnosis literature [33], participants in the
293 study referred to the concept of ‘patient activation’ [34]. They articulated their need or willingness and
294 ability to take independent actions to manage their health and care throughout the diagnostic period.
295 Similar to what has been discussed in the context of treatment and survivorship [35], the healthcare
296 system, even in the pre-diagnosis period, is increasingly complex, with a growing number and variety of
297 specialties, care delivery sites, and diagnostic tests. In the face of navigating these complexities, and in
298 the context of the psychological burdens of potentially facing cancer it is not surprising that many
299 patients and families find crucial to advocate for getting their care needs met [32]. In order to fully
300 benefit from the care available to them and have improved experiences, patients and families promote
301 their own interests and actively try to avoid situations such as delayed appointments with a specialist or
302 delayed access to appropriate testing.

303

304 As acknowledged by participants and supported by previous research, in order to be able to advocate
305 for themselves, patients and family members need to be involved with individuals and groups that
306 support their interests [32, 33]. Unlike post-diagnosis, before diagnosis patients are not “cancer
307 patients” yet and they and their family members do not hold membership into particular patient/family
308 groups that can provide this support, leaving healthcare providers as the main group who can do it.
309 While at post-diagnosis stages oncology care teams are an important source of support to patients and
310 families [36], before diagnosis patients expect this role to be played by family doctors. Family doctors in
311 Canada play a key role in helping to manage and coordinate care for patients before and after diagnosis
312 [37], and as suggested by our findings their engagement from the beginning of the patients’ journey in
313 helping them navigate the diagnostic period and advocating for them when required is important. We
314 heard from participants that it is important for patients/families to feel that family doctors are on their
315 side and support them. Family doctors can support patient and family members willing to engage in self-
316 advocacy behaviours by trying to establish deeper connections with them and adequately informing
317 them. As reported in previous research, family doctors are a primary source of information during the
318 diagnostic period [15], and patients need to feel adequately informed in order for them to participate
319 effectively in making decisions throughout the diagnostic period [32]. Based on our findings, optimal
320 attention to patient and family needs may include hearing their concerns, providing them with regular
321 updates on the investigation process, engaging in discussions of expectations about the different steps
322 involved in the diagnostic period, and assessing their understanding of these conversations. Finding
323 ways to promote and support family doctors in the care of potential cancer patients throughout the
324 diagnostic period and equipping them with the skills and tools required to better support them should
325 be explored further.

326 **Limitations**

327 The findings of this study should be considered in light of some limitations. First, the study was not
328 longitudinal and results are particular to the time frame the interviews were conducted. Distress and
329 recovery from the diagnostic period is a dynamic process, the perspectives of patients and family
330 members would likely be different at an earlier or later point in time. Their perceptions may have
331 changed as more time elapsed since the date of diagnosis. Second, the information was collected
332 retrospectively and data might be subject to memory recall errors. Finally, as in any study involving self-
333 reported data, results may be subject to exaggeration and attribution. Despite these limitations, results
334 from this exploratory study provide important contributions to this area given the limited number of
335 studies focused on perceived timelines and challenges during the diagnostic period.

336

337 **Conclusion**

338 In an effort to streamline the diagnostic period in Alberta, Alberta Health Services and other
339 stakeholders have established streamlined diagnostic programs for breast, lung and prostate cancers
340 [38-40]. The Cancer Strategic Clinical Network is currently initiating a program to establish an Alberta
341 Facilitated Cancer Diagnosis Strategy that goes across cancer sites and geographies in the province. Our
342 study asked patients and family members in the province about their experience from symptom to
343 cancer diagnosis and found that they struggled emotionally. Findings complement quantitative studies
344 that described long and variable periods from suspicion to diagnosis for different cancers [8-10].
345 Findings suggested that from the perspectives of patients and family members shorter times to
346 diagnosis are desirable, but many additional factors also need to be considered for improved
347 satisfaction with care. Supporting individuals deal with a prospective cancer diagnosis by facilitating
348 access to lived experiences with the diagnostic process and cancer, and enhancing the supportive role of

349 family doctors may improve outcomes for patients and family members. Although this study helps shed
350 light on how to improve the experiences of patients and family members during the diagnostic period,
351 more work is required to understand how some of the psychosocial supports available to cancer
352 patients after diagnosis could be used to support these patients and their families before diagnosis.

353

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358

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470 **Supporting information**

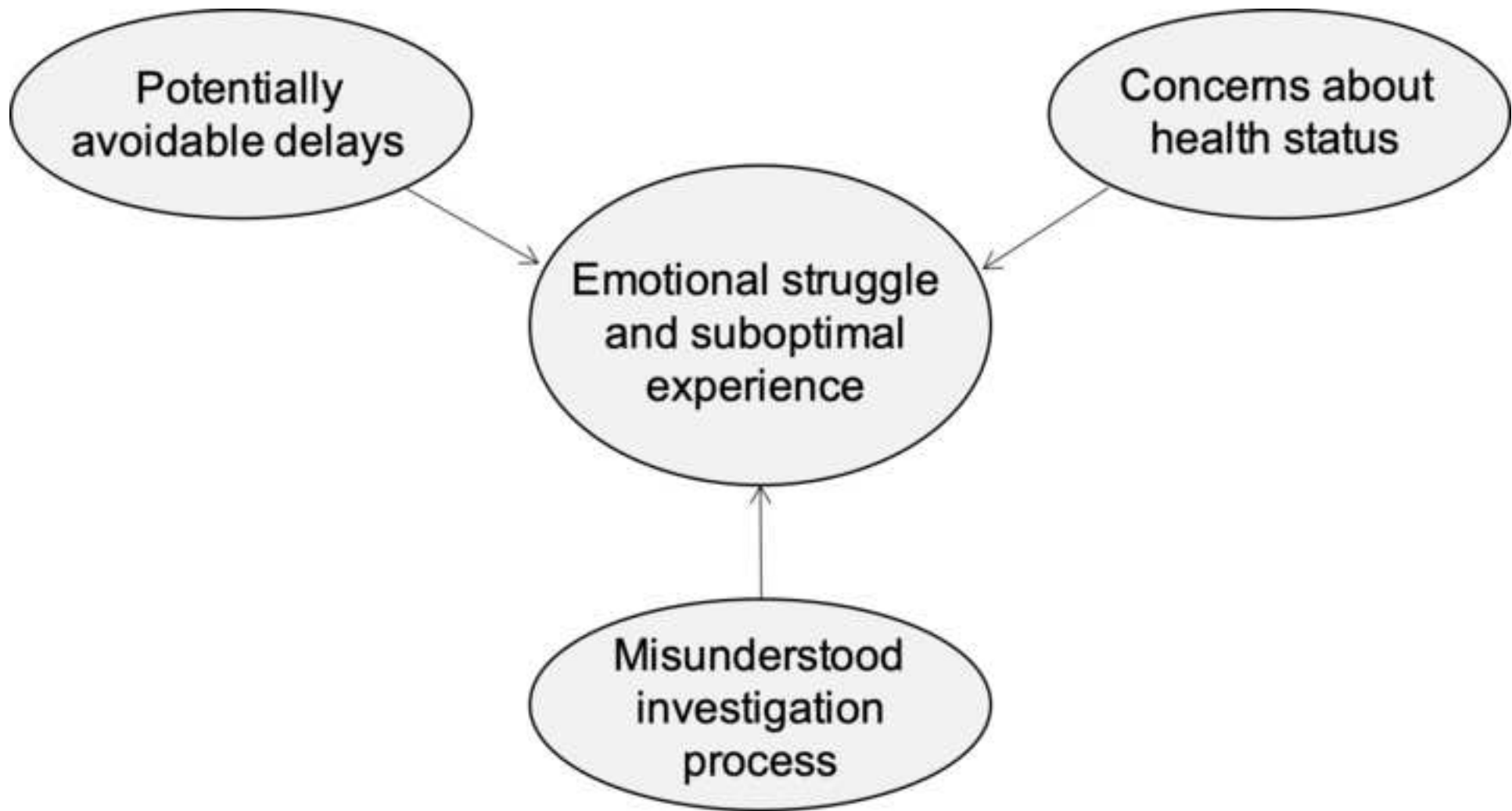
471 **S1 Appendix. Semi-structured interview protocol (patients)**

472

473 **S2 Appendix. Semi-structured interview protocol (family members)**

474

475 **S3 Fig. Emergent themes relevant to cancer patients and family members' experience during the**
476 **diagnostic period**





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